UNIVERSITY OF ALBERTA

MOTHERS' AND FATHERS' RESPONSES TO SIDS

BY

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A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

IN

COUNSELLING PSYCHOLOGY

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

SPRING 1998

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Mothers' and Fathers' Responses to SIDS submitted by Moira Linden Sacks in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Counselling Psychology.

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Dedicated to
my husband, Herbert, with thanks for his love and belief
that each person is able to achieve their dreams and
ideals, and to our children, Juliette, David, and Adele
who have brought so much joy and pleasure into my life.

ABSTRACT

The goal of this study was to learn more about how mothers and fathers deal with the death of a baby from Sudden Infant Death Syndrome. Lists of the ways mothers and fathers responded after the baby's death were collected in response to an open ended question in the form of (i) mailed out questionnaires, (ii) interviews, and (iii) telephone interviews. Using the method of concept mapping, each list of statements was analysed into ten themes. The ten themes found for mothers were (i) getting and sharing information, (ii) finding out that I am not alone, (iii) coming to terms with the baby's death, (iv) looking forward to a new baby, (v) doing normal things, (vi) putting it out of my mind, (vii) questioning beliefs, (viii)remembering the baby, (ix) getting comfort through being alone, and (x) being sad, angry and grieving. The ten themes for fathers were (i) talking, (ii) getting support from others, (iii) trying not to think about it, (iv) seeking comfort and understanding, (v) distancing, (vi) feeling fear and helplessness,(vii) being sad and depressed, (viii) accepting the baby lived and died, (ix) remembering the baby, and (x) seeking closure.

Mothers and fathers reported a variety of statements. Seventy percent of the statements were shared by both parents: 30% reflected gender biases and individual differences. The recovery processes for mothers included grieving, making changes, getting on with life, and remembering the baby. For fathers, the recovery process included grieving, accepting the baby's death, and making changes. Both parents experienced much pain and sadness. Fathers did talk. Mothers sought professional help and for some, having another baby was part of the recovery process. Guilt was not theme in this study.

ACKNOWLEDGEMENTS

I wish to express my most sincere thanks to all those who helped me in so many ways to make the completion of this thesis possible. My grateful thanks and appreciation to Dr. Peter Calder for his support, encouragement, and careful supervision throughout the research study and preparation of the thesis. I acknowledge the help and critiques of the members of the Dissertation Committee: Dr. Richard Sobsey, Dr. Len Stewin, Dr. Louise Jensen, and Dr. Barbara Paulson. A sincere thanks to Dr. Gretchen Hess and Dr. Jane Drummond for their constructive critiques, support and encouragement.

I am deeply grateful to the executive of the Edmonton Chapter of the Canadian Foundation for the Study of Infant Death and all the parents who participated in this study. I was profoundly moved by the stories you shared and the courage you had to revisit a very painful time in your lives. Thank you.

Thank you to my friends and colleagues who assisted by helping with the sorting process. To Dr. Sheila Mansell, Dr. Linda Chorney and Dr. Lynda Grant, thank you for your support and encouragement. I am most appreciative and thankful for the invaluable computer expertise and support of Andre Zawallich.

A very special thank you to my husband, Herbert, and children, Juliette, David and Adele for your love, encouragement and support throughout this journey. Knowing you were there at all times, made this whole venture more meaningful and helped keep my life relatively normal. Thank you for your patience through the difficult times; now we can celebrate and try to find a new normality!

I would also like to acknowledge and thank the University of Alberta for the travel scholarship that allowed me to participate in the Fourth International SIDS Conference in Washington in 1996.

TABLE OF CONTENTS

Page

CHAPTER 1: INTRODUCTION 1
- SIDS and its aftermath 1
- Focus of the study 6
- Purpose of the study 7
- Assumptions and limitations 8
- Summary 8

CHAPTER 2: LITERATURE REVIEW 10
- The nature of SIDS 10
- The extent of the problem 11
- Causes of and risk factors for SIDS 12
- The parental pain of SIDS 15
- Grief and gender differences 16
- Sex-role stereotype and grief/coping 18
- Effects of differences in parental responding/coping 19
- Gender differences in response to other crises 22
- Coping and grieving 23
- Rationale for the study 24
- Concept mapping: Method of choice 29
- Concept mapping method 30

CHAPTER 3: METHODOLOGY 33
- Part one: Concept mapping 33
  - Generation of statements 34
  - Structuring of Statements 37
  - Data analysis 38
- Part two: Gender comparison 40

CHAPTER 4: RESULTS 42
    Part one: Mothers' and fathers' responses to their baby's death 42
        Themes of mothers' and fathers' statements 44
        Description of mothers' concept map 59
        Description of fathers' concept map 66
        Prevalence of themes for mothers and fathers 74
    Part two: Gender comparison 85
        Differences in mothers' ways of responding 91
        Differences in fathers' ways of responding 92
        Frequency of use of statements 93
        Concept map comparison 101
            Mothers' concept map 101
            Fathers' concept map 103

CHAPTER 5: DISCUSSION AND CONCLUSION 106
    Discussion 108
        Mothers' experience 110
        Fathers' experience 116
    Conclusions 121
    Limitations of the study 123
    Practical implications 123
    Future research 124

REFERENCES 126

APPENDIX A 135
APPENDIX B 136
APPENDIXES C and D 137
APPENDIX E 138
APPENDIX F 139

APPENDIX G 140
APPENDIX H 141
APPENDIX I 143
APPENDIX J 149
APPENDIX K 153
APPENDIX L 160

LIST OF TABLES

Table 1	Demographic characteristics of participants.	43
Table 2	Master list of mothers' statements.	45
Table 3	Master list of fathers' statements.	47
Table 4	Cluster items and bridging indices for mothers.	52
Table 5	Cluster items and bridging indices for fathers.	55
Table 6	Distribution of mothers' endorsements of statements for each cluster.	75
Table 7	Distribution of fathers' endorsements of statements for each cluster.	80
Table 8	Comparison of coping statements generated by mothers and fathers.	86
Table 9	Frequency of use of mothers' statements	94
Table 10	Frequency of use of fathers' statements	98

LIST OF FIGURES

Figure 1	Mothers' point map	49
Figure 2	Fathers' point map	50
Figure 3	Mothers' concept map: 10 cluster solution.	60
Figure 4	Fathers' concept map: 10 cluster solution.	67
Figure 5	Mothers' 10 cluster concept map, categorized into major themes.	102
Figure 6	Fathers' 10 cluster concept map, categorized into major themes.	105

CHAPTER 1: INTRODUCTION

When a baby dies, each individual in the family begins a unique journey that will change the course of her or his life in a host of profound ways.
(DeFrain, J., 1991, p. 215)

SIDS and its Aftermath

The death of one's own infant or baby is a traumatic and tragic event for the parents and family. No matter the circumstances of the death, the parents are thrown into a period of confusion and pain. The ensuing experience is devastating, and filled with intense emotions and great suffering. This time of grieving or bereavement is a process of learning to deal with the loss and integrating the loss into one's life so that it has meaning (Arnold & Gemma, 1991). Parental grief is painful and personal (Martin, 1993), and may cause on-going distress for years after the death of the child (Lehman, Wortman & Williams, 1987).

Parents who have lost a child experience great intensities of bereavement that place some parents at risk for a complicated grieving response and difficulties in returning to normal living. In fact, parental bereavement may not diminish over time but intensify in the third year of bereavement (Rando, 1983). The unexpectedness of the sudden death of a child exacerbates the bereavement process; the shock of the child's death reduces the bereaved parents' coping abilities and may prolong their return to full functioning (Sanders, 1988). Parents and children in families where a child has died accidentally or as a result of murder may suffer Post Traumatic Stress Disorder (PTSD), and according to Applebaum and Burns (1991, p. 119) the "... sudden loss of a sibling may reciprocally 'infect' one another with anxieties and fears related to the trauma". Following a sudden infant death, parents "struggle with post traumatic stress reactions and grief concurrently" (Dyregov, 1996, p.6).

Lehman, Wortman, and Williams (1987) concluded from their study into the sudden accidental death of a child that mourning for a deceased loved one likely continues for the rest of the parents' lives. Parents are filled with intense feelings of sadness and loss regardless of whether death follows a long illness or is sudden and unexpected. In their study Dyregov & Matthiesen (1987) reported that the early grief reaction to the unexpected death of an apparently healthy baby (SIDS) is more severe for parents than those when the child is stillborn or is a neonatal death. In addition, parents who experience a SIDS death suffer from pervasive feelings of guilt.

The major cause of death for infants aged 1 week to 1 year in the USA is from SIDS, which accounts for between 7,000 to 10,000 infant deaths annually (DeFrain, Taylor, & Ernst, 1987; Rando, 1991; Worden, 1991). Valdes-Dapena (1991, p.2) notes that "...In Canada, the problem is equally distressing - the rate is virtually identical": two babies die as a result of SIDS for every 1000 live births. Martin (1993), citing data from Statistics Canada for 1989, reported that 254 boys and 138 girls died of SIDS in Canada. She concludes that each year in Canada approximately 400 babies die suddenly and unexpectedly for no apparent reason. Dent, Condon, Blair, and Fleming (1996) state in their study of sudden and unexpected death in England that "although the number of children is small, the numbers of those affected by the deaths are not" (p.7). The death of an infant is a major life stressor.

In Canada, 400 fathers and 400 mothers are at risk for a longer grief reaction which includes suffering from intrusive images and anxiety soon after the infants' deaths (Dyregov & Matthiesen, 1987). Compared to mothers, fathers returned to normal functioning earlier (Cornwell, Nurcombe, & Stevens, 1977) and attained a greater level of personal happiness one year after the death (DeFrain, 1991; DeFrain & Ernst, 1991). Women tend to be more emotional, to cry and want to talk about the baby or child, compared to men (Mandell, McAnulty & Reece, 1980).

Although much of the literature on child death suggests that grieving responses of mothers and fathers are different, Rando (1983, p.18) states that "...mothers and fathers are more similar in their grief than previously noted." According to Lazarus (1993), men and women have similar types of coping patterns to work, health, and family-related stress. The differences reported between the way mothers and fathers grieve may result from the majority of studies having focused on the mothers; more information is needed to clarify fathers' grief responses.

Both mothers and fathers grieve the death of their children. According to Gilbert (1989), the majority of studies on parental grief have been researched from a maternal viewpoint with the husband being a potential source of support. Mothers have been the major contributors to the current research; as a result little information is available about fathers' responses to their babies' deaths. In one study, 109 mothers completed surveys compared to 18 fathers (DeFrain, Ernst, Jakub, & Taylor, 1991). In Price, Carter, Shelton, and Bendell's (1985) study the majority of responses from forty-one fathers were incomplete and so the fathers' data were excluded and data from seventy-three mothers were used. Although questionnaires were mailed to both spouses in a study researching grief after a SIDS death, all responses returned were from the mothers (Ostfeld, Ryan, Hiatt, & Hegyi, 1993).

However, there are studies which look at the differences between mothers and fathers. In a study of SIDS, 85% of the parents indicated their "personal approach to grieving was different from that of their spouses" (DeFrain, 1991, p.221). When a child dies, parents are often expected to support each other and they look to one another for the meaning in the death of their child. This support may not be available and each parent may construe different meaning to their loss (Gilbert, 1989). The death of a child, particularly the unexpected sudden death of an apparently healthy baby, impacts painfully on the parents and creates great stress.

Dyregov (1996) suggests that the type of death rather than the suddenness, explains the strong parental reactions: parents usually find the baby themselves and so are exposed to a series of visual impressions. As a result of being unprepared for this death, the parents' coping abilities are severely taxed and this may lead to difficulties between couples and for the family (Worden, 1991). Parents' ability to cope may further be compromised by their not knowing the cause of death, and they desperately search to find out why their baby died (Arnold & Gemma, 1991).

Information on grieving and coping has been derived from qualitative studies using questionnaires (DeFrain, 1991: DeFrain, Ernst, Jakub, & Taylor, 1991) or from studies limiting the information collected to questions posed by certain instruments (Dyregov & Matthiesen, 1987). Qualitative data have not been used as research data but rather as quotations to illustrate or "flesh out their statistical analysis" (Martin, 1998, p. 41). However, DeFrain (1991) collected data from several studies and recorded the data as the ten most common questions asked by parents whose baby died from SIDS. Qualitative data has been used to illustrate parental experiences and provide comfort to other parents (DeFrain, Taylor & Ernst, 1987; DeFrain, Ernst, Jakub, & Taylor, 1991), summarized into issues (Mandell, McAnulty & Reece, 1980), and used to share the story, not as "lifeless statistics" (DeFrain & Ernst, 1978, p. 8).

Other studies have used questionnaires composed of numerous questions and/or specific inventories. The study by Dryegov and Matthiesen (1987) used a questionnaire and five inventories to examine parental grief; they described eight grief reactions. Price, Carter, Shelton, and Bendell (1985) used a mailed out questionnaire that focussed on the grief symptoms, social support and marital adjustment of mothers whose baby died from SIDS. Symptoms of grief, sources and use of social support, marital relationships and the effects on children were investigated using a questionnaire by Ostfeld, Ryan, Hiatt, and Hegyi (1993).

A review of the qualitative literature of how parents cope when a baby dies from SIDS reveals no phenomenological or grounded theory studies on this topic. Studies using inventories, checklists, and questionnaires suffer from an inherent limitation of the conceptual domain being examined. A preponderance of the studies are about the grieving responses and coping strategies of mothers. Fathers, when mentioned, are often subsumed under the term "parents"; even discussions of couples are largely about mothers. Therefore there is a need to more clearly conceptualize, in a systematic way that minimalizes researcher bias and without the constraints of using questionnaires or selected instruments, the ways in which both mothers and fathers respond to the death of their baby from SIDS.

Focus of the Study

Few empirical studies on how parents cope following SIDS are found in the literature. Each parent has a unique perception of their loss and to fully understand their responses to that loss requires that they report their own perceptions of their experience (Gill & Feinstein, 1994). Thus, in a study of parental coping, it is appropriate for mothers and fathers to define how they perceived that they dealt with the death and for the data to be analyzed systematically. Concept mapping is such a technique.

Concept mapping is a method which permits the analysis of descriptive data in a systematic way that results in the data being clustered into themes that are represented visually. This method results in understanding psychological issues as experienced by the participants rather than as defined by the researcher (Daughtry & Kunkel, 1993: Trochim, 1989 a/b). The statistical analysis of qualitative data by concept mapping has the advantage of bringing objectivity to qualitative data that may have been analysed before using non-statistical methods (Kunkel, 1991). Concept mapping acts as a bridge between qualitative and quantitative research, and permits the conceptualization of those "things" that are implicit in a situation or experience. This technique has not been reported in the literature as having been used to describe parental responding following a SIDS death: concept mapping will result in the conceptualization of the nature of the experience for mothers and fathers whose infant died of SIDS.

Purpose of the Study

The significantly stressful period for parents following sudden infant death and the possible long term grief process indicate that a clearer understanding of the parental experience of SIDS is of importance. There is a particular need to address how fathers respond to their babies' deaths. The purpose of this research is to describe the the ways in which fathers and mothers respond to their baby's death from SIDS. Concept mapping will be used to conceptualize fathers' and mothers' responses as visually represented themes. Data resulting from concept mapping will be used to determine if there are any differences in responses of fathers and mothers to SIDS.

The study was designed to answer the following questions:

1) What did parents do to deal with the death of their baby from SIDS?
2) Into what themes do the the reported responses fall?
3) Are there gender differences in the reported responses?

It is hoped that this study will help to clarify the ways mothers and fathers respond to the death of their infant from SIDS, and that this information may suggest better ways to provide support for both bereaved men and women. In addition, a greater knowledge base for counselling professionals may increase the possibility that counsellors will have appropriate expectations of what is attainable in the therapeutic process, and provide therapeutic interventions that will be beneficial for the parents and their families. A better understanding of mothers' and fathers' experiences following the sudden death of an infant, will also be of value in the development of programmes for support groups.

Assumptions and Limitations

Participants in this study were recruited from the local chapter of the Canadian Foundation for Study of Infant Deaths. The data gathered from these participants may reflect a certain group of SIDS parents and may not reflect the experiences of those who did not respond to the questionnaires or who were not members of a support group. Therefore the results of this study may have limited generalizability.

The babies of the parents who participated in the study died from one year and 10 months to approximately 16 years prior to the study being conducted. The varying times since death and the respondents' reliance on memory may result in data that reflects inference and interpretation. Painful memories tend to be forgotten with the passage of time resulting in the underreporting of painful memories.

Those individuals who consented to be interviewed were members of the executive committee of the support group which in turn could create a potential selection bias.

Summary

Qualitative data used in previous studies to investigate grieving and coping responses in SIDS parents have not been used as true research data. Fathers have been under represented when researchers refer to participants as "parents." In this study, qualitative data will be systematically analyzed by the method of concept mapping for mothers and fathers respectively. The experiences examined in this study are those generated by the participants and are free from the constraints of issues imposed by quantitative instruments. Results from this study will complement other studies and provide a clearer understanding of how mothers and fathers respond to the death of their baby from SIDS.

The subsequent chapters of this thesis will be of the following format: In Chapter 2, literature pertinent to parental grief and coping with infant death, gender differences in coping, and the use of concept mapping is reviewed. Chapters 3 and 4, describe the method and results. Finally, conclusions, discussion, practical implications and implications for future research of the research findings are provided in Chapter 5.

CHAPTER 2: LITERATURE REVIEW

This chapter begins with a brief outline of the current understandings of the nature of SIDS. Then reviews the literature on parents' responses to their babies' deaths from SIDS, and the implications of gender differences in coping with stressful situations. A model of coping is described. Then the rationale for this study and selected method of investigation is presented. Finally, a brief explanation of concept mapping is provided.

The Nature of SIDS

There is no exact epidemiology or consensus as to the cause of sudden infant death syndrome; the cause of SIDS is unknown (Klonoff-Cohen & Edelstein, 1995; Peterson, 1988). The uncertain nature of SIDS adds to parents' and health care professionals' discomfort when coming to terms with the unexpected death of an apparently healthy baby. Although as long ago as biblical times there are references to sudden infant deaths, SIDS has only been defined as a medical entity causing death since 1969 (Ranney, 1991; Valdes-Dapena, 1991). Dalveit, Oyen, Skjaerven, and Irgens (1997) conclude from their Norwegian survey identifying risk factors in SIDS between 1967-93, that SIDS is "an epidemilogical entity which should be studied from both an aetiological and preventative point of view " (p. 26).

In 1989 a panel of the National Institute of Child Health and Human Development defined SIDS as follows: " the sudden death of an infant under one year of age which remains unexplainable after a thorough case investigation, including performance of a complete autopsy, examination of the death scene and review of the clinical history" (Willinger et al., 1991, cited in Krous, 1995). Many consider the current definition to be too broad. There is a need for a precise definition to allow professionals and researchers to identify SIDS cases. On the other hand, a less restrictive structure benefits parents as a diagnosis of SIDS removes the guilt from their caregiving (Krous, 1995). The diagnosis of SIDS is by exclusion. Some of the typical patterns that may be considered in making a diagnosis are that deaths usually occur between midnight and 9.00 a.m., during cold periods of the year (Valdes-Dapena, 1991), and with babies placed to sleep and found on their stomachs (Klonoff-Cohen & Edelstein, 1995). The necessity of death scene investigation and autopsy to make a diagnosis and exclude death by abuse may add to the pain and stress experienced by the bereaved parents.

The Extent of the Problem

Fortunately, SIDS is not common. According to Peterson (1988) the number of deaths from SIDS is 0.5 - 3.0 per live births. Deaths from SIDS occur in babies between the age of 1 week to 1 year, with the majority of deaths occurring between 2 - 4 months of age (Valdes-Dapena, 1991). Annually in the USA, SIDS accounts for between 7,000 and 10,000 infant deaths (DeFrain, Taylor & Ernst, 1987: Rando, 1991: Worden, 1991). In Canada the death rate from SIDS is identical to that of the USA; approximately two babies die for every 1,000 live births (Valdes-Dapena). SIDS is the cause of death for 50% of all deaths of infants aged between 2 and 4 months (Klonoff-Cohen, 1995).

As is the case for other childhood diseases, male babies appear to be more vulnerable than female babies. Hence more baby boys than girls die from SIDS each year (O'Brien, 1993; Valdes-Dapena,1991): This is reflected in Statistic Canada data for 1989 that indicate 254 boys and 138 girls died from SIDS (Martin, 1993). The impact of sudden infant death is substantive. While the lack of a definitive cause may add to parents' distress, it has set in motion a wide range of research by many different disciplines.

Causes of and Risk Factors for SIDS

One of the main difficulties in studying SIDS is that there are no living individuals to study and progress is slow (Hillman, 1991). While research is in progress, the final decision as to whether death is from SIDS lies in the hands of the pathologists at autopsy. Pathologists may have some difficulty in coming to their conclusion as to cause since research has suggested numerous possible causes of death. Robertson (1988) believes that for SIDS to occur there is a "window of vulnerability during which major development of vital biological functions take place" (p. 13) and that death results from a failure of some aspect vital to life. O'Brien (1993) proposes a neurological model for SIDS: Under stressful conditions, the instability of rapidly developing neural systems makes babies vulnerable to SIDS. Other research has focussed on respiratory control centres of the brain stem, control of the upper airways, bronchospasm or end expiratory apnea, and cardiac arrhythmias (Hillman, 1991).

Considerable research has been directed at determining risk factors for SIDS. Several risk factors are now well documented: (i) fetal/maternal risk factors such as poor prenatal care, smoking during pregnancy, use of illegal drugs, social economic status and ethnicity; (ii) environmental factors such as low temperatures, prone sleeping position, and inappropriate bedding and clothing; and (iii) infant factors such as low birth weight, history of near death accidents, obstructive apnea, and infections/illnesses (O'Brien, 1997: Williams et al. 1996).

Most recently, emphasis has been placed upon the baby's sleeping position, with many countries promoting "Back to Sleep" campaigns. The decreasing habit of placing babies in the prone position for sleep is reported as being contributory to the reduction in SIDS deaths in countries such as Australia, United Kingdom, Sweden, Norway and the Netherlands (Blair, et al. 1996; Dalveit, Oyen, Skjaerven, & Irgens, 1997; Dwyer & Ponsonby, 1997; Vandenplas, Belli, Dupont, Kneepkens, & Heymans,1997). From the Australian studies, Dwyer and Ponsonby conclude that the prone sleeping position for babies accounts for 50% of SIDS deaths. However, Klonoff-Cohen (1997) argues that a reduction in use of the prone sleeping position has not resulted in a similar decrease in SIDS deaths in the USA although she states that the 30% decrease in SIDS fatalities between 1993 - 95 were attributed to the "Back to Sleep" campaign.

A growing amount of evidence has accumulated implicating smoking as a risk factor in SIDS. Studies conducted in California and the United Kingdom confirm that the risk of SIDS increases if the mother smokes during pregnancy, if the mother smokes in the baby's environment, and as the number of smokers in the home increase (Blair et al., 1996; Klonoff-Cohen et al., 1995). In both studies a positive dose response was found; the more tobacco smoked the greater the risk for SIDS. According to Blair et al. there is an additive effect if the mother smoked during pregnancy and continues smoking after delivery. Based on statistical calculations, these authors claim that not smoking can reduce the number of SIDS deaths by two thirds. Breastfeeding provides no protection to babies exposed to smoking (Klonoff-Cohen et al.). The use of alcohol and/or illegal drugs such as cannabis have been found to increase the risk of SIDS (Blair et al.).

The incidence of SIDS varies among different cultural groups. African Americans, Native Americans, Australian aboriginals and Maoris have higher rates of SIDS compared to Caucasian Americans with Hispanics having fewer SIDS deaths than Caucasians, and Asians having the lowest number of deaths (Kelly & Shannon, 1982; Klonoff-Cohen & Edelstein 1995; Valdes-Dapena, 1991). Different incidence of SIDS between ethnic groups may be attributed to cultural differences in child care practices (position in which the baby is placed for sleep) (Klonoff-Cohen & Edelstein) or result from socioeconomic status of these groups (Valdes-Dapena). Mothers being under 20 years of age and unmarried is another risk factor for SIDS (Dalveit, Oyen, Skjaerven & Irgens, 1997; Kelly & Shannon, 1982; Klonoff-Cohen & Edelstein).

A number of risk factors can be modified by providing parents with knowledge or education about SIDS. Evidence comes from studies that caring parents may inadvertently put their babies at risk. Williams et al. (1996) found that during cold spells or infant illness, parents increased the amount of coverings or clothes on their child which resulted in hyperthermia and so placed the baby at risk for SIDS. Primarily, thermal stress puts babies sleeping in the prone position at risk. Even so, risk factors are not, "in and of themselves" the cause of SIDS and avoidance of those implicated does not prevent death: SIDS is considered unpredictable and unpreventable (Horchler & Morris, 1994, p. 5).

The fact that some risk factors can be modified by a change in care giving practices or parental behavior may add to the pain parents suffer when their apparently healthy infant dies unexpectedly. Evidence that some SIDS deaths may in fact result from abuse (Newlands & Emery, 1991) or infanticide (Emery, 1985) can make coping with SIDS even more difficult for parents. Understanding how both mothers and fathers cope with the unexpected death of an apparently healthy baby is important in providing support and help for the parents and their family unit.

The Parental Pain of SIDS

No matter the circumstances, the death of a healthy baby is a devastating loss for the parents. Parents suffer terribly when their baby dies suddenly and for no apparent reason. When the possible diagnosis is a SIDS death, parents' agony and pain may be exacerbated by the questions and the coroner's autopsy. For each parent the grief is painful and personal (Martin, 1993), and a time of great loneliness about which many individuals are unable to speak (Bohannon, 1991). Evidence is accumulating that SIDS parents grieve for years after their baby's death. According to Lehman, Wortman and Williams (1987) the sudden death of a child up to the age of 18 years may cause long lasting distress that is a common response rather than an indication of parental inability to cope. When their child dies, parents are faced with issues that make their period of grieving particularly difficult to resolve (Rando, 1985). Some of these difficulties may arise from spouses perceiving certain coping behaviors in their partner as being uncaring or from the expectation that sharing the same death, both spouses will grieve in similar ways. Bereavement is exceedingly painful and long lasting for parents whose child dies, and may place some parents at risk for a poor out come (Sanders, 1988).

In a study investigating the reaction of parents to stillbirth, neonatal death and SIDS, Dyregov and Matthiesen (1987) reported higher levels of distress in SIDS parents up to 4 years post death compared to the other groups. In addition, based on the mean scores of a number of psychological measures that included the Impact of Event Scale and Goldberg General Health Questionnaire, these authors reported higher incidence of early grief, anger, anxiety, sleep disturbances and intrusive thoughts among SIDS parents than when a baby is stillborn or is a neonatal death. The trauma of a SIDS death is a very stressful life event that leaves the parents suffering from intrusive images and thoughts, and feelings of guilt (Dyregov & Matthiesen; Dyregov, 1996). Parents stated in DeFrain and Ernst's (1978) study that coping with a sudden infant death to be the most severe crisis experienced . However, there is no consensus in the literature as to whether mothers and fathers deal with their infants' deaths in similar or different ways. Rando (1983) believes that both men and women are similar in their grieving while Sanders (1988) suggests that there is a sex difference in coping with the death of an infant.

Grief and Gender Differences

According to the results of responses to mailed out questionnaires, DeFrain and Ernst (1978) concluded that SIDS parents took an average of 15.9

months to regain their level of happiness prior to the death. Prior level of happiness was a very subjective measure as it was dependent on each participant's own concept of this. DeFrain (1991) describes a slight lag for mothers behind fathers in the level of happiness during the first year following the death of a baby, but after that recovery is almost identical. Cornwell, Nurcombe, and Stevens (1977) reported that it took mothers 10 months to feel as though they were functioning normally compared to less than 4 months for fathers. A study investigating the effects of child death on parents using a bereavement questionnaire determined that the mean grief intensity ratings of mothers were greater than for fathers, that parents grieved more for the death of healthy children, and male children were grieved more than female children (Littlefield & Rushton, 1986).

Following the death of a child from cancer, Bohannon (1990-91) found that from their score on the Grief Experience Inventory husbands "seemed to grieve at lower levels of intensity" (p. 119) and to have significantly higher levels of denial than their wives. Williams and Nikolaisen (1982) report that fathers more readily accept the diagnosis of SIDS than do mothers. Mothers are more likely to dream, think, and look at baby mementos (Cornwell, Nurcombe, & Stevens, 1977), to participate in support groups than fathers (Mandell, McAnulty, & Reece, 1980), and to oppose another pregnancy (Gilbert, 1989). The literature suggests that mothers and fathers have different coping styles. Women may communicate their grief by being "open and emotional" (DeFrain, Taylor, & Ernst, 1987, p. 29); this takes the form of crying and wanting to talk about their experience (DeFrain, Ernst, Jakub, & Taylor, 1991). Fathers use a more active coping style which involves keeping busy and increasing their work loads (Mandell, McAnulty ,& Reece,1980). Men revert from the use of emotional expression back to general male coping styles more quickly than mothers do to their general female styles (Littlewood, Cramer, Hoekstra, & Humphrey, 1991).

One assumption about grief is that it is a universal process that can be understood irrespective of the context of loss across all adult ages and relationship contexts (Clark, 1993). If this is true, then mothers and fathers would process death in the same way. It is not clear however that the differences are due to gender-role or to biological differences between males and females.

Sex-role Stereotype and Grief/Coping

Certain behaviors in our society are deemed to be male or female and conformity to these beliefs is perceived as necessary for societal acceptance. Sex-role stereotyping is evident in children from about 3 years of age (Franks & Rothblum, 1983) and continues to influence individuals throughout their lives. Mothers and fathers have traditionally played different roles as parents. The nature of the mother's role creates an experience with her child that may be quite different to the experience shared by the father. Mothers may feel that life no longer has a purpose after the death of her child. DeFrain, Taylor, and Ernst (1987) suggest that "young mothers are bound to have conflict feelings about the helpless infant and worry about their maternal role" (p. 54). Fathers, who are less involved in child care, are less likely to question their role in the infant's sudden death, but their feelings may centre on feelings of having spent too little time with the child (DeFrain, Taylor, & Ernst).

Following the death of their child, fathers are in a double bind. Males, having learned from childhood to hide their feelings, take the stereotypical role of caretaker and being strong for the mother, and in addition may have to go to work to provide for the family (DeFrain, 1991). The picture of male grief and coping may be more one of male role stereotyping. People grieve differently. Therefore it is likely that mothers and fathers express their grief differently and this may affect the marital relationship. When a child dies, parents are often expected to support each other and to look to one another for meaning in the death of their child. This support may not be available and each parent may construe a different meaning to their loss (Gilbert, 1989).

Effects of Differences in Parental Responding/Coping

Both parents suffer from the same death and therefore expect that their grieving response will be the same. Differences in parental response to the death of a child may cause conflict and difficulties within the marital relationship. Conflict may arise between couples when one partner misunderstands the way the the other is grieving (Gilbert, 1989). Since men are more likely to use active coping as a response, they may want their wife to use the same style of coping. For example one husband who coped with his grief by working more and becoming involved in many activities tried to manage his wife's grief by "persuading her to take evening classes every night of the week" (Littlewood, Cramer, Hoekstra, & Humphrey, 1991, p. 146). Such conflict adds to the parental pain and stress, and may result in divorce. However, DeFrain (1991) reports that only 4% of SIDS parents divorced as a result of their child's death but parents, whose role is defined by societal expectations (i.e. husband as the breadwinner and wife as the aggrieved) experience much bitterness. However, in their study investigating differences in the ways each spouse coped with the death of their child from SIDS, Carroll and Shaefer (1993-94) found that mothers and fathers "acknowledged" their loss but dealt with their feelings in different ways. They concluded that these differences helped to maintain the martial relationship.

Differences in grieving response or style affect the father in other ways. Dyregov and Matthiesen (1987) report that hospital staff respond more sympathetically to emotional styles of coping than to active coping styles. Since men tend to use active coping, fathers report feeling "overlooked". One father recounts "I was supposed to provide great amounts of support for my mourning wife.... Everywhere I turned I received the same advice. Only two people mentioned concern for me during this period" (DeFrain, Taylor, & Ernst, 1987, p.28).

If a man were to express his grief, this may be considered an inappropriate behavior for his gender. However when a man does not show his grief, he is considered to be unable to do so. Expectations of "being strong" may place restrictions on the way fathers feel comfortable expressing their emotions. Such attitudes combined with the role of being breadwinner put fathers in a double bind. Coping with this double bind may result in fathers not showing emotion, appearing to recover from their child's death more quickly than their wives, and not talking about their experiences. A popular belief is that men are unable to express their suffering while women are a model for healthy grieving by talking and crying. However, if a man were to show his feelings, this may be considered by some as inappropriate male behavior (DeFrain, Taylor, & Ernst, 1987). It would seem that here again men are in a double bind: accepted healthy emotional expression of pain is unacceptable for men and consequently their way of dealing with such situations is either attributed to their suffering being less or different to their wives'.

Benfield, Lieb, and Vollman (1978) reported that fathers showed significantly lower grief scores than mothers. Bohannon (1989) found fathers, after a child had died from cancer, had lower scores on most grief indicators and higher scores for denial; the high score for denial may reduce the fathers' grief scores. While these studies reflect in a rather negative way on fathers' capacity for grief, this does not mean that fathers do not grieve or suffer from their child's death. However, fathers tend to feel alone or left out of the family's grieving, want time to grieve, and may want to grieve in private (DeFrain, Taylor, Ernst, 1987). The literature about the way fathers grieve and cope with the death of their child is not entirely clear. Fathers' ways of coping may be confused with sex-role stereotyping.

Each spouse feels the pain of the death of their baby in a personal way. Male family members "are likely to suffer as much from the death as females" (DeFrain, 1991, p. 229). In coping with their tragic circumstances, it is necessary to understand that each spouse may respond differently but this does not mean without pain. The descriptions of male coping with SIDS are inadequate in the literature and more information is required to better understand both what happens at a personal level as well as between couples. The literature on gender differences in coping with other stressful situations may shed some light on the gaps on how fathers cope with the death of a child from SIDS.

Gender Differences in Response to Other Crises.

Studies on children's response to stressful life events such as violence between parents find that boys display aggressive (externalizing) behaviors compared to girls who demonstrate anxious, depressed (internalizing) behaviors (Jaffe, Wolfe, Wilson, & Zak, 1993). Stressful life events for boys of elementary school age are strongly associated with anxiety, aggression and submissive withdrawal compared to girls who do not exhibit obvious changes in adjustment (Hoffman, Levy-Schiff, & Ushpiz, 1985). Adult men and women are perceived to express their mental disorders in distinct ways that reflect what happens in childhood. Females tend to internalize distress and males exhibit personality disorders and have problems with alcohol and/or drugs (Ensminger & Celentano, 1990). Harris (1992) suggests that the way in which males and females respond to aggression reflects the different behavior members of each sex used in their past, with males experiencing more aggressive situations both as instigator and target. However, when men and women were exposed to a natural disaster, men were more adversely affected. When additional heavy demands for nurturance were made on women, this impacted detrimentally on the women's mental health (Solomon, Smith, Robins, & Fishbach, 1987).

Unemployment is another major life stressor for which gender differences are found in coping. Although unemployment has an negative effect on the psychological well-being of both males and females, the impact is greater on males (Muller, Hicks, & Winocur, 1993). In their study of

Australian clerical workers, unemployed men suffered from more tension and fatigue than women. Muller, Hicks, and Winocur postulated the negative impact on males is consistent with the "idea that males see employment central to their masculine identity" (p. 107). When men and women have similar role configurations, few gender differences are found for psychological distress related to unemployment (Ensminger & Celetano, 1990).

Coping and Grieving

Contrary to public prejudices, Lazarus (1993) contends that men and women have similar ways of coping for health, work, and family-related stress. Coping is what people do to manage stress (Lazarus & Lazarus, 1994), and it is coping that shapes the individual's emotions (Lazarus, 1993; Lazarus and Lazarus). According to the model of coping proposed by Lazarus (1993), the cognitive-appraisal of the person-environment relationship results in the generation of emotion, and that appraisal determines the content (e.g. anger, guilt, anxiety) and the intensity of the emotion. In this model there are three possible variants of psychological stress: harm/loss, threat, and challenge. The sudden death of an infant is an irrevocable loss which, in effect, has the "dramatic plot of sadness"; all the parents can do is grieve and move on (Lazarus & Lazarus, p. 78).

Appraisal results in the individual assessing the significance of what is happening in terms of the individual's own well-being (Lazarus, 1993). Cognitive appraisal includes both primary and secondary components: secondary appraisal involves the determination of (i) attributions (ii) coping potential (iii) future expectations (Lazarus). Coping is contextual and is either problem-focused or emotion-focused (Lazarus; Lazarus & Lazarus, 1994). Problem-focused coping results in changes to the environment or to one's behavior. Emotion-focused coping is the way an individual changes his/her thinking about the problem: avoidance, denial, distancing (Lazarus & Lazarus). This type of coping is "internal and private" and is used to control "distress and the dysfunction it might cause when there is little or nothing else we can do" (Lazarus & Lazarus, p. 156).

Coping with loss results in struggle and protest that cause individuals to experience combinations of emotions: anger, anxiety, guilt, shame, hope (Lazarus & Lazarus, 1994). Emotions are part of coping and are part of grieving. Grieving is a process and therefore takes time. Worden (1991) describes four tasks of mourning: accepting the reality of the loss, working through the pain and suffering, adjusting to the environment without the deceased, and emotionally relocating the dead and moving on with life. Parents who have lost a baby from SIDS experience many emotions as they grieve and cope in the aftermath of the baby's death.

Rationale for the Study

The majority of studies on grieving have focussed on widows or mothers' responses to the death of a child (Gilbert, 1989; Littlewood, Cramer, Hoekstra, & Humphrey, 1991; Martin, 1993). The way in which fathers grieve and cope with their child's death has been neglected in research. One reason given for this is that both society and the medical community have traditionally viewed the mother-child bond as exclusive and as a result have devalued fathers' roles. Another reason has been that fathers do not like to talk or express their emotions publicly, accounting for the dearth of information (Mandell, McAnulty, & Reece, 1980).

Most studies investigating parental grieving or coping with the death of a child over-represent mothers' ways of dealing with this painful situation. In the work of DeFrain, Taylor, and Ernst (1987), the majority of recorded stories are told by mothers. Martin (1993) notes that 83% of the parental sample are mothers in the research of DeFrain, Ernst, Jakub, and Taylor (1991) while DeFrain's (1991) sample was composed of 328 mothers and 88 fathers. From a total of 46 families, a total of 28 fathers participated in a study by Mandell, McAnulty, and Reece (1980). Lehman, Wortman, and Williams (1987), in a study of accidental child death, reported that 67% of their sample were mothers. Another study reports that 73 mothers out of 242 families that had experienced the death of a child from SIDS returned completed questionnaires; only 41 fathers responded and many of their questionnaires were incomplete (Price, Carter, Shelton, & Bendell, 1985). As a result, the Price et al. study only reported mothers' responses. Videka-Sherman (1982) mailed separate questionnaire packets to each spouse in her study of coping with the death of a child but her ultimate sample consisted of 70% females.

Specific information about fathers' ways of coping may have become hidden under the umbrella of "parents." Research, to date, has focussed primarily on the mothers' responses to grieving and on the mothers providing other information. Limited information is available about fathers' grieving response to SIDS. This may reflect their lack of willingness to talk about such an emotional experience, the fact that fathers have been viewed as support systems for the mother (Gilbert,1989) or that fathers' active coping style allows them to avoid dealing with painful issues (Price, Carter, Shelton & Bendell, 1985).

The majority of the data collected on parental coping has come from questionnaires, various rating scales, checklists, inventories, and parent interviews (DeFrain, Taylor, & Ernst, 1987; Dyregov & Matthiesen, 1987; Defrain, 1991). DeFrain, Taylor, and Ernst report that they used a qualitative approach where parents communicated their experience of SIDS in their own words. These authors used the parents' words not as research data to be analyzed but to be presented as people's "real life" stories to inform and comfort other parents. DeFrain (1991) collected the information gathered from 9 studies to reflect the 10 most common questions asked following the death of a child. In Mandell, McAnulty, and Reece's (1980) study community health nurses visited the SIDS families, assessed the parents' reaction to their child's death and reported the results as "observations on patterns of paternal grief" (p. 221).

In addition to questionnaires, some researchers have used other instruments such as The Impact Event Scale, Beck Depression Inventory, State-Trait Anxiety Inventory (Dyregov & Matthiesen, 1987), the SIDS Parent Coping Inventory (Carroll & Shaeffer, 1993-94), and the Grief Experience Inventory (Bohannon, 1990-91; Kindrachuk, 1993; Littlefield & Rushton, 1986; Rando, 1983). Gilbert (1989) examined the grief resolution process of parents after infant death using a semi structured interview with open-ended questions while Lehman, Wortman, and Williams (1987) specifically designed an interview instrument to assess depression and the psychological well-being of parents following the death of a child in a road accident.

Instruments assess various aspects of the grief experience: some measure intensity of feelings, some determine common experiences, and some may be recorded numerically. Mailed questionnaires provide privacy for parents and reach a large heterogeneous group (DeFrain, Taylor, & Ernst, 1987). Some of these methods make it difficult to achieve an understanding of the parents' experiences. While open-ended questions in questionnaires provide a means to tap the "pain and sorrow", face-to-face interviews provide opportunities for the deeper exploration of issues (Martin, 1993, p. 54). The qualitative approach allows for the exploration of the richness of both the mother's and father's personal grief experience; these experiences require closer examination to explore gender or sex-role components.

It is difficult, if not impossible, to compare current research on the responses of parents to the death of their child. The majority of studies have not been comparative, although Lehman, Wortman, and Williams (1987) used a control group of non-bereaved parents. However, the research on parents' grieving after the death of a child from non-SIDS causes is not directly comparable because of the great variation in causes of death, ages of the children, ethnicity, and time elapsed since death. For example, Littlefield and Rushton (1986) used a sample consisting of parents whose children were aged 0 - 45 years, had died from various causes, and who had been interviewed 3 months to 13 years after the death. Even when studies focused on parents' grieving after a death from SIDS, differences in the ethnicity of the parents, the ages of the infants at death, and time elapsed since death are variables that may make comparison difficult. In one study of parental response to SIDS, the sample consisted of infants of 5 different age groupings, deaths had occurred during a "period of several months", and 24 of the infants who had died were white, 2 were black and 2 were Hispanic (Mandell, McAnulty, & Reece, 1980, p. 221). This mixed ethnic grouping assumes that all parents will respond in similar ways; no accommodation has been made for cultural differences. Although the majority of published studies appear to involve Caucasian families, Klonoff-Cohen and Edelstein (1995) report that in California, the highest incidence of SIDS is in African Americans and North American Indians.

Review of the literature reveals that existing qualitative studies lack rigorous, systematic analysis. Other studies have restricted the collection of data by using specified questions or inventories that may limit the domain being studied. In addition, the majority of studies have gathered information about mothers' grieving and coping after a baby has died from SIDS. Little information is available about fathers' coping. In 1985, Price, Carter, Shelton, and Bendell stated that no empirical data existed about grief reactions in fathers whose baby died from SIDS; little has changed since then. The general lack of empirical data in the literature on how mothers and fathers cope with the sudden death of their baby confirms the need for studies to clarify this situation. The current information on how parents cope after a baby dies from SIDS creates a fragmented picture. The coping responses of mothers and fathers who lose a child are of significant importance for those individuals and their families. A systematic, descriptive study of responding to the sudden death of an infant by both mothers and fathers could begin to address this issue. This study is an attempt at such a beginning.

Concept Mapping: Method of Choice

Research into the how parents cope following a sudden infant death investigates very sensitive and painful issues. Martin (1993) argues that the most appropriate approach for this type of study is by using qualitative methods. A qualitative approach results in the subjective exploration of an experience or phenomenon but the information may be contaminated by the researcher's own abilities and beliefs (Morse & Field, 1995; Palys, 1992). Gill and Feinstein (1994) concluded that instruments alone were not sufficient to determine quality of life issues and that it is necessary to obtain the individual's perception on their health status. Goodwin and Goodwin (1984) argue that the research method chosen should be the best one to answer the research question; this may be a combination of both the qualitative and the quantitative approaches.

While previous studies have generated considerable information, much of the information presents a rather diffuse picture of parental responding with many isolated facts and no frame work upon which to organize them. There is a need to more clearly conceptualize how mothers and fathers respond to SIDS. Utilizing both qualitative and quantitative approaches is a blend that Oberle (1991) posits as possibly being the most satisfactory model for educational and psychological research. A method that uses both qualitative and quantitative approaches is concept mapping (Daughtry & Kunkel, 1993). Concept mapping allows data to be analysed in a systematic way with minimal bias from the researcher (Trochim, 1989b). In addition, Trochim (1989a) states that concept mapping can be used as the basis for developing theory and may reveal the implicit theory of a process

(Trochim, 1989b).

Trochim (1989b) used concept mapping as an evaluation tool and explained the methodology as being a sequence of steps that resulted in statistical order being given to descriptive data. Concept mapping has also been used to gain an understanding of educational issues (Chorney, 1997; Chorney, 1994), as well as in psychological research such as the experience of depression in college students (Daughtry & Kunkel, 1993), the impact of Multiple Sclerosis on marital relationships (Grant,1997), and the experience of Tourettes Syndrome on the individual and family (Zawallich, 1997).

Concept mapping is a procedure that employs statistical techniques that result in statements being clustered into themes. It identifies the underlying structures and the constituent elements in a phenomenon shared by a group of individuals (Trochim, 1989b). Other advantages of concept mapping are that it uses data in the form of the participants' perceptions of the experience (Daughtry & Kunkel, 1993), that researcher bias and subjectivity are reduced by using numerous sorters (Rosenberg & Kim, 1975 cited in Trochim, 1989b), and that the interrelationships and concepts within the experience are represented graphically (Trochim). The collection of descriptive data unconstrained by the researcher's preconceptions, followed by the systematic analysis of that data resulting in a conceptualization of the way mothers and fathers respond to SIDS makes concept mapping a particularly appropriate method for this study.

Concept Mapping Method

Concept mapping as described by Trochim (1989b) is a six step process:

1) selecting participants and developing the focus of the study, 2) generating statements, 3) structuring the statements, 4) representing the statements as concept maps, 5) interpreting the lists and maps, and 6) utilizing the maps.

In the preparation phase, individuals who are knowledgeable about the issue are selected as relevant participants. In concept mapping, a heterogeneous sample of participants can be an advantage in that it makes it more likely that the broadest possible range of experiences within a particular conceptual domain will be collected. In past studies using concept mapping, participants have formed broad heterogeneous groups, relatively small homogeneous groups or been randomly sampled from a larger population (Trochim, 1989b). Sample size for concept mapping can be as small as one or vary from 4 - 75 (Trochim, 1989a), 3 - 6 (Valentine, 1989), or 10 - 20 (Linton, 1989). The focus for the study is determined by a carefully and clearly worded question (Trochim, 1989b).

In response to the research question statements reflecting participants' perceptions of the question are gathered. Trochim (1989b) states that data for concept mapping can be gathered from textual documents, organizational memos, interviews and field notes. Statements generated from a one-question questionnaire were used in a study of teacher stress (Chorney, 1997), and the same type of questionnaire plus interviews by Grant (1997) in a study of Multiple Sclerosis. Ideally, statements generated reflect the entire conceptual domain of the research question. Statements from all participants are collected and combined until redundancy; redundancy is the point when no new unique statements are being collected. Trochim suggests that the maximum usable statements not exceed 100, as it becomes difficult to sort large numbers of statements into thematic groups.

Once a list of statements has been compiled, sorters are asked to allot statements into piles having a common theme. The sorters are given instructions that place restrictions on the way the cards are sorted but are to sort them "in a way that makes sense to you" (Trochim, 1989b, p. 5). Interrelationships between statements are identified as a result of this card sorting process. Statements that are conceptually similar will tend to be sorted into the same piles.

The sort data are analysed using multidimensional scaling and cluster analysis through the concept mapping software resulting in cluster lists, point maps and concept maps (Trochim, 1993).

Cluster statements that are relatively frequently sorted together are examined and given a label reflecting the underlying themes in their content. Sorters may be involved in deciding the names for the themes. The concept map is a visual representation of the various themes; clusters that are conceptually similar are located closer to each other on the map (Trochim, 1989b).

The resulting concept maps can be used to understand a phenomenon or issue and for planning and evaluation of treatment programs. Each concept can stand alone for future research or the original statements can be included in a questionnaire for further investigations (Trochim, 1989b).

CHAPTER 3: METHOD

The purpose of this study was to extend the understanding of the experiences of parents whose baby died from SIDS from the parents' perceptions. The specific objectives were 1) to identify the ways in which mothers and fathers responded to their child's death, 2) to determine and identify the underlying themes in the mothers' and fathers' responses, and 3) to determine and identify any gender differences in parental responding. In order to meet the above objectives, this study was carried out in two parts: the first two objectives were investigated in part one and the third objective in part two.

Prior to commencing the study the proposed method was approved by the Ethics Review Committee of the Department of Educational Psychology for use with the sample population.

Part One: Concept Mapping

Concept mapping, as described by Trochim (1989b), allows qualitative data to be analyzed in a systematic manner. This method involves the generation of statements in response to a specific research question, the structuring of statements results from statements being sorted into themes by a group of sorters, and the analysing of statements by multivariate techniques. The result is the pictorial representation of the statements as themes or clusters, in the form of point maps and cluster maps. Finally the point maps, cluster maps and cluster lists are interpreted. Data, collected independently from mothers and fathers, were treated as described above.

Generation of Statements

Data for this study were collected from participants as statements of how they remembered dealing with the death of their baby. The study involved participants (12 mothers and 11 fathers) who had experienced the death of a baby from SIDS. The Edmonton Chapter of the Canadian Foundation for the Study of Infant Deaths (CFSID) was contacted and their mailing list made available. Three couples responded to the research question in face-to-face interviews, and two chapter members (not a couple) and one couple (non SIDS chapter members) participated in telephone interviews.

Mothers and fathers generated statements to the open ended question "What did you do to deal with the death of your baby from SIDS?" in one of three ways:

1) mailed out questionnaires
2) in depth interviews
3) telephone interviews

1) Questionnaires.

Eighty participants from the CFSID mailing list were mailed a package containing a letter of introduction (Appendix A), a description and purpose of the study (Appendix B), and two forms, one for mothers and one for fathers, on which to record their responses to the research question (Appendixes C and D). Participation in this study was strictly voluntary, discontinuation was possible at any time and completion of the questionnaire was viewed as consent to participate in the study. No signature was required and so anonymity was ensured. If one member of the couple did not want to participate, the other partner was asked to complete and return the appropriate questionnaire.

Participants were asked to respond to three demographic questions and one open-ended question. The demographic information required was 1) the age of the baby at time of death, 2) time since the death of the baby, and 3) birth order of this baby in the family. In response to the open-ended question "What did you do to deal with the death of your baby from SIDS?" participants were asked to list all the ways (actions, thoughts and feelings) they had used to deal with their babies' deaths.

2) Interviews.

Data was collected from three couples by means of face to face interviews. Two of these three couples were interviewed by tape recording their responses in the absence of their partner. The purpose and nature of the study was explained to each interviewee (Appendix B) and they were asked to sign the Consent to Participate form (Appendix F). Aspects of confidentiality and anonymity were discussed, and the participant was informed that on completion of the study the tape would be destroyed. Participants were also informed that their decision to participate was voluntary and that they could withdraw at any time.

The third couple had received the mailed questionnaire but requested that the researcher be present when providing their responses. In this case, the potential participants were made aware of the purpose and nature of the study by information received with the questionnaire (Appendix B). Consent was their responding to the open-ended question on the questionnaire in the researcher's presence. The participants' responses were hand recorded in point form on the questionnaire sheet. The hand recorded responses were repeated back to the participant for verification. Each member of the couple was interviewed in the absence of the other partner.

The tape recorded responses were transcribed. Statements were highlighted and removed from the transcriptions to form lists of statements maintaining the language of the participants. Where necessary, the context of the statement removed from the transcription was noted by inserting appropriate word(s) in brackets, and information irrelevant to the research question was removed. This resulted in a list of statements for each interviewed participant.

3) Telephone interviews

The purpose of the study, anonymity and confidentiality were explained to the four participants who agreed to a telephone interview. It was made clear that participation was voluntary and that they could withdraw at any time. Consent to participate was taken as their responding to the demographic questions and the open ended question.

The responses of the telephone participants were recorded by hand in point form, and the recorded information read back for verification. Two participants were a marital couple and they were requested to respond with the other partner absent from the room in which they were speaking.

Ways in which Mothers and Fathers Responded to their Baby's Death

Statements from mothers and fathers were collected to the point of redundancy when no further statements containing significantly new, meaningful information were gathered (Appendixes I and J). At this point, data collected is deemed to adequately reflect the domain being sampled. The 239 mothers' and 161 fathers' statements were edited. All identifying references and statements not relating to the research question were removed. The 239 statements generated by the mothers were then edited so that each numbered line contained one statement eg. "I went to the library and read all the books" became "I went to the library" and "I read all the books". Editing resulted in some statements being reworded for grammatical accuracy or for clarity or brevity eg. "I had to muster up every ounce of strength and will power I could to keep myself going and try to be positive in carrying on with life" became "I had to be positive in carrying on with life". This editing process resulted in a list of 287 statements for mothers (Appendix K) and a list of 164 statements for fathers (Appendix L). Where there were several statements representing a similar idea, one was chosen resulting in a list of unique statements for mothers and fathers respectively; these were the master lists.The master lists of statements for mothers and fathers contained 80 and 78 statements respectively (Tables 2 and 3).

Structuring of Statements

The statements from each master list were printed on slips of paper that were a convenient size for handling. The sorting process required each independent sorter to place either 80 mothers' statements or 78 fathers' statements into piles of statements that made sense to the sorter. According to the restrictions described in Appendix H, sorters were instructed to sort the statements in any way they liked such that the groupings contained a common theme. The sorters were requested to staple each group of like statements together and to record the items placed together in each group on the record sheet. In addition, the sorters were encouraged to suggest names describing their themes.

Lack of response from participating SIDS parents to help in the sorting process resulted in using sorters who were parents but were not SIDS parents. These parents received the information presented in Appendix G. Ten mothers and twelve fathers sorted the SIDS mothers' and the SIDS fathers' coping statements, respectively.

All ten completed sorts by mothers were used in the data analysis of mothers' statements: eleven out of the twelve completed male sorts were used in the fathers' data analysis. One male sorter placed the statements into only three piles. This sorting was therefore excluded from the data analysis, in accordance with Weller and Romney's, (1988, cited in Trochim, Cook, & Setze, 1994) recommendation that individuals who produce large generic categories ("lumpers") or very discrete categories ("splitters") be excluded.

Data Analysis

Analysis of the resulting sorts was carried out using "The Concept System" (Trochim,1993), a computer program that uses multidimensional scaling to place the sort statements into clusters representing themes. The sorted mothers' and fathers' data were analyzed in the same way but independently of each other.

Point maps were produced as a result of this analysis process. Each statement is identified by a number and is represented as a point on the point map by X-Y co-ordinates. The loci of the statements is determined by the sort data. The distance between points reflects the frequency with which those statements were sorted together. Statements that appeared to be conceptually more similar were sorted more frequently into the same pile and therefore are located closer together on the map. Conversely, statements that were considered less similar were less likely to be piled together and appear further apart. Point maps were produced for mothers and for fathers respectively.

The point map was further divided into clusters that represent conceptually similar statements by superimposing specified cluster solutions on the MDS point map as a result of hierarchical cluster analysis (Trochim, 1989b). The ensuing map is a concept cluster map. In this study, the objective was to determine concept maps that would be useful in drawing conclusions about gender in responding to sudden infant death. The following procedure was employed to select the most suitable mothers' and fathers' concept maps. The number of clusters was determined by the researcher examining the possible cluster solutions that made conceptual sense. A cluster solution that yielded interpretable clusters was obtained by the process of examining successively higher or lower numbers of clusters between 2 to 18 clusters. Simultaneously, the items within the statement groupings and their bridging index values were examined for conceptual consistency. Based on the most conceptually coherent groupings of the data, the best mothers' and fathers' concept maps were selected. The concept clusters in both maps were assigned names according to the themes inherent in each cluster.

Part Two: Gender Comparison

The third objective of this study was to determine whether the statements used by mothers and fathers were the same. To this end, the master lists of statements for mothers and fathers were examined for similarity of content. As well, the concept maps produced by mothers and fathers were examined for similarity.

The first step in the comparison of mothers' and fathers' master lists was to identify statements made by both mothers and fathers that were considered to be equivalent in meaning or intent. In those cases where a statement began with the pronoun "we", it was taken that "we" implied the pronoun "I" as the statements reflected actions taken by a couple in dealing with the death of their baby. Equivalency of statement was determined by the use of the same or similar verb, expressed similarity of intent ("I kept my self busy." is similar to "I spent a great deal of time playing the piano.") or reflected a similar theme ("I kept a lot of the baby's clothes." and "I remember the baby's birthday and Christmas."). Four psychologists acted as inter-raters in finalizing the comparisons drawn between mothers' and fathers' statements.

The next step was to examine the frequency of use of statements generated by this group of mothers and fathers respectively. Frequency tables were compiled by referring back to the original statements collected from mothers and fathers (Appendixes I and J) and determining whether each individual had used one of the statements on the appropriate gender master list.

Finally, the mothers' and fathers' cluster concept maps were examined for similarities and differences by grouping together clusters that reflected a common theme. This grouping process required the researcher to make logical decisions as to the placing of the regional boundaries (Trochim, Cook & Setze, 1994; Trochim, 1989b). The cluster themes within each region were examined for an underlying theme or process, and then named accordingly. The regions designated on the mothers' and fathers' concept maps were compared for similarities and differences.

CHAPTER 4: RESULTS

The purpose of this study is to gain an understanding of how mothers and fathers respond after the death of their baby from SIDS. The aims of this research were to determine 1) the ways in which both mothers and fathers responded to their child's death 2) the themes of mothers' and fathers' responding, and 3) to identify any gender differences in responding. The first two objectives were studied using concept mapping. In the second part of the study information about gender and responses were derived by using results gained in part one. The results obtained for these three objectives are presented in this chapter.

Part One: Mothers' and Fathers' Responses to their Baby's Death

Data was collected in the form of statements from 12 mothers and 11 fathers who had lost a baby from SIDS. Of this group, 9 participants were couples. Eighty questionnaire packages were mailed out: Six fathers and seven mothers returned completed questionnaires over a 5 week period. This reflects a 7.5% return rate for fathers and a 8.75% return rate for mothers. The questionnaire return rate is lower than the low end of the 10 - 40 % expected: a low return rate is a problem if a representative sample is required but not when using a heterogeneous one (Palys, 1992). The Edmonton Chapter of the CFSID historically reports a return rate of less than 10% for surveys (Executive, Edmonton Chapter, CFSID, 1996, personal communication).

Demographic information about the sample population is shown in Table 1. The age of babies that died ranged from 1 month to 5 months, and were predominately male babies; both of these facts fits for a diagnosis of

Table 1.

Demographic characteristics of participants.

Participant	Age of baby at death (months)	Time since death (years)	Sex of baby	Birth order
Father 1	4	6	male	1
Mother 1	4	6	male	1
Father 6	3	1.83	female	3
Mother 2	3	1.83	female	3
Father 10	5	12	NK	3 (last)
Mother 3	5	12	NK	3 (last)
Father 4	4	7	male	2
Mother 4	4.5	7	male	2
Father 11	2.5	2.5	male	1
Mother 5	2.5	2.5	male	1
Mother 12	1.75	16	male	2
Father 2	2.5	10	male	2
Father 7	1.75	15	NK	NK
Mother 8	2.25	15	male	3
Father 3	2.5	7	male	1
Mother 6	2.5	7	male	1
Father 8	1.5	14	male	2
Mother 7	1.5	14	male	2
Mother 11	2	3.5	NK	2
Father 5	2	12.33	male	3
Mother 9	2	12	male	3
Father 9	1	15	male	3
Mother 10	1	15	male	3

NK = not known (gender of baby not included in demographic questions; sex determined from use of pronouns in responses).

SIDS. The majority of SIDS deaths in this population were in families who already had children; another risk factor for SIDS is that it occurs with increasing number of births in a family (Dalveit, Oyen, Skjaerven, & Irgens, 1997). Time since the death of their babies ranged from just under 2 years to 16 years.

Information was collected from mothers and fathers who responded to the question "What did you do to deal with the death of your baby from SIDS?" by means of questionnaires, interviews and telephone interviews. After editing the parents' statements, two master lists were compiled: the mothers' list contained 80 statements and the fathers' list, 78 statements (Tables 2 and 3).

Themes of Mothers' and Fathers' statements

The two master lists of statements collected were used in the concept mapping process described by Trochim (1989 a/b) to identify themes of responding. The final stress values for the two dimensional solutions of the MDS analysis were 0.30 for mothers and 0.29 for fathers. The stress value is an index of stability of the MDS solution: the stress value ranges from zero (perfectly unstable) to one (perfectly stable). Both the stress values obtained indicate reasonable stability of the solutions. Trochim, Cook, and Setze (1994) reported an acceptable stress value of 0.31 for their two dimensional solution of the MDS analysis. Daughtry and Kunkel (1993) accepted a stress value of 0.27 to be "reasonably stable" in their study describing depression in college students.

Point maps were produced from each set of sort data (Figures 1 and 2).

Table 2

Master list of mothers' statements in response to the question "What did you do to deal with the death of your baby from Sudden Infant Death Syndrome (SIDS)?"

1 I talked to parents who had lost a child.
2 We got help from the minister.
3 I talked to my spouse.
4 I talked to my spouse's mother.
5 I talked to my children.
6 I got to see my baby.
7 I had lots of support from family and friends.
8 We went away.
9 I did normal things.
10 I went for counselling.
11 I went to the doctor for information and advice.
12 I took medications.
13 I was hospitalised.
14 I kept myself busy.
15 I would go out.
16 I put it out of my mind.
17 I went back to work.
18 I read everything I could find on SIDS.
19 I asked the coroner some questions.
20 I wanted everybody to know what SIDS is.
21 I found it nice to know that someone else had these feelings and had gone on.
22 We found out what other people did with the baby's body.
23 I made the funeral arrangements.
24 I asked "Why had this happened?"
25 I went to the funeral.
26 We brought the baby's remains home.
27 When I saw the baby at the funeral, there was something missing.
28 I phoned the SIDS 24 hour line.
29 I went to the SIDS support group meetings.
30 I took the babysitter to the support group meetings.
31 I raised money for SIDS.
32 I was on the Board of Directors of the SIDS chapter.
33 I volunteered.
34 I was very angry.
35 I cried.
36 I had a lot of guilt.
37 I would get depressed.
38 I was devastated.
39 I blanked out major blocks of time.
40 I was overwhelmed with grief.
41 I felt very lonely and empty.
42 I was hurting.
43 I got very emotional hearing stories from new SIDS parents.

Table 2 (continued)

44 I cried and wondered if it was a baby when I heard sirens.
45 I felt I wasn't alone after reading other people's stories.
46 I wanted the children to leave me alone.
47 I had to look after my other children.
48 I became very close to my spouse.
49 I was relieved to know that my spouse was still grieving and still cared about the baby.
50 I was pregnant again.
51 I felt the best thing for me was to have a baby.
52 I tried to have another child.
53 You know in your mind that you are still a mother but physically there is no baby.
54 We adopted a baby.
55 We moved.
56 We cleaned everything in the house before the next baby arrived.
57 I accepted the situation.
58 I had the next baby sleep in our room.
59 I know that the baby's death is not anything that people have done.
60 I blame God.
61 I became indifferent to God.
62 I asked God's help.
63 I know the baby is in heaven.
64 I had to go on.
65 I could see babies and not turn away.
66 I distanced myself from babies.
67 I shared the baby pictures with friends.
68 I sent everybody copies of the funeral.
69 I read the sympathy cards.
70 I kept a journal.
71 I kept a lot of the baby's clothes.
72 I looked through the baby's things.
73 I shut the door and left the baby's room as it was.
74 I try to remember as much as I can.
75 I sat in the baby's room.
76 I questioned whether there was something wrong with me when I laughed.
77 I check my children and my husband when sleeping.
78 I find it easier acknowledging that the baby lived.
79 I went to national SIDS conferences.
80 I did in-services for Victims Services.

Table 3

Master list of fathers' statements in response to the question "What did you do to deal with the death of your baby from Sudden Infant Death Syndrome (SIDS)?"

1 I talked to friends at work.
2 I did a lot of talking about it.
3 I talked to people.
4 I talked to a relative.
5 I talked to others who understand because they have lost a baby.
6 I talked to my spouse.
7 I did not talk that much to my spouse.
8 I don't talk about it a lot.
9 I drank more after the baby died.
10 I exercised or did physical work.
11 I did a lot of day dreaming and thinking.
12 I worked to keep my mind from thinking about it.
13 I spent a great deal of time playing the piano.
14 I didn't work any more.
15 I prayed a lot.
16 We called family and friends.
17 I had support of family and friends.
18 We went away with my spouses' relatives.
19 I lost track of time.
20 I visited the grave.
21 We kept the baby's door closed.
22 We had a funeral.
23 I didn't go to the cremation.
24 When I saw the baby laid out, I knew my child was not in that body.
25 I was glad when I knew the body was gone.
26 I am happy having the baby's cremated remains in a warm house full of love.
27 I cried and cried for a long time.
28 I almost had a break down.
29 I really felt depressed.
30 I felt overwhelming emptiness.
31 I was devastated.
32 I had a hard time.
33 Sometimes I really hurt.
34 I was angry.
35 I felt a sense of heaviness.
36 I fought with my spouse.
37 I gave my spouse a hug.
38 I helped my spouse get over it.
39 I became closer to my spouse.
40 I felt helpless to help my spouse.
41 I had to look after the older children
42 I always acknowledge the baby as part of the family
43 We had a new baby.

Table 3 (continued)

44 I found it hard with the next baby
45 I was afraid that the same thing would happen to our next baby.
46 I said to hell with religion.
47 I said "God you've always said that you'll be there for us".
48 We began to go to church.
49 I like to think that I do everything in the baby's name.
50 I thought I wouldn't be lucky enough to have children after the baby died.
51 I thought God never figured I was a good enough parent so he took my baby away from me.
52 We asked "Why did a little baby go?"
53 I'll meet my baby in heaven.
54 I'll know and understand everything when I get to heaven.
55 I think that life must go on.
56 I believe that there is nothing that we could have done.
57 I think my baby has been spared.
58 I have a little angel on shoulder that protects me on bad days
59 I organized the 24 hour SIDS line.
60 I run as many parent support groups as I can make
61 I turned first to the minister.
62 I found the SIDS group very helpful.
63 I phoned the SIDS help line.
64 Knowing that others have lived through the experience makes you see that you can live.
65 I needed to understand.
66 I asked questions at the SIDS meetings.
67 I found the emergency response team very sympathetic, helpful and protective.
68 I watched films about SIDS.
69 I was scared to death to see my friend's baby.
70 I checked the next baby three to four times during the night.
71 The first thing I do when I come home or wake up is check the children.
72 I would wake up at night and check that my wife was breathing.
73 I knew the baby was gone.
74 I couldn't understand, the world wasn't stopping, mine had.
75 I had bad dreams.
76 I remember the baby's birthday and Christmas.
77 I decided that the quality of life was more important than work.
78 I remember the last night I spent with my baby.

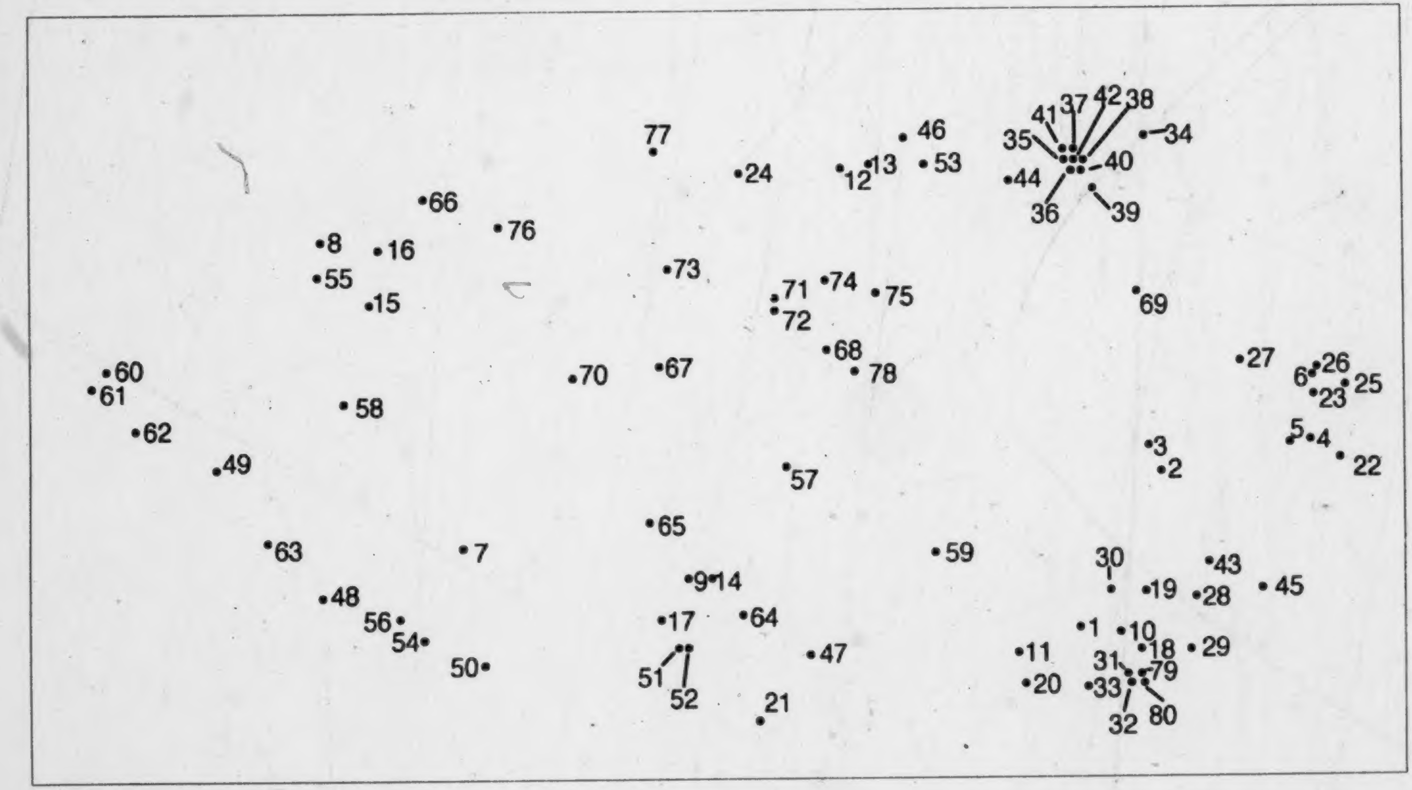


Figure 1
Mothers' point map.

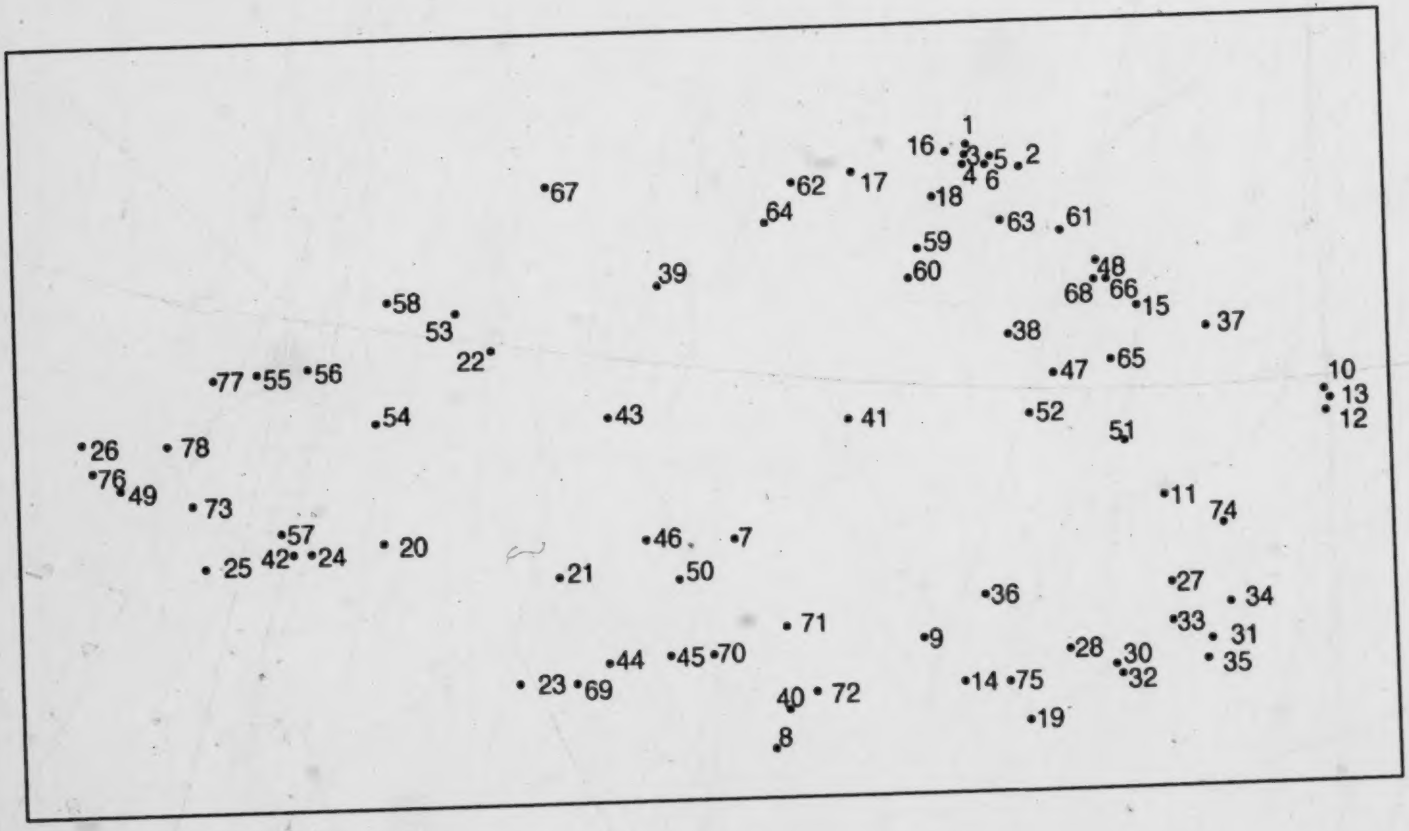


Figure 2
Fathers' point map.

The resulting point maps provide pictorial representations of the manner in which sorters grouped the statements. The distance between the points on the point map reflects the frequency with which statements were sorted together (Daughtry & Kunkel, 1993). Statements that are conceptually similar are closer together. Each numbered point represents a statement.

Using the Concept System, concept cluster maps consisting of 10 clusters for both mothers and fathers respectively were chosen to most logically describe their responding. Cluster solutions of less than 10 were considered to be unsatisfactory since the diversity within the clusters was too great. Solutions with clusters in excess of 10 were too fragmented or narrow. The choice of the 10 cluster solutions was facilitated by reference to the bridging index of each statement.

The computer program computed bridging indices for each statement and each cluster. A bridging index is a number between 0 and 1.0 that is a statistical measure of the relationship of one statement to another in the group. A lower bridging index indicates that a statement was more likely to be sorted with other statements close to it, while a higher index represents statements that were frequently sorted with various other items on the map. Statements having the most central meaning for a cluster have low bridging indices (Trochim, 1993). A low average bridging index for a cluster indicates that the cluster is more coherent than clusters with high bridging indices. Clusters with high bridging indices are considered to be "linking" clusters between adjacent clusters (Trochim, 1993). The statement groupings for the 10 cluster solutions for mothers and fathers concept maps are shown in Tables 4 and 5.

Table 4

Cluster items and bridging indices for ten solution concept map for mothers whose babies died from SIDS.

		Bridging index
Cluster #1: Getting and Sharing Information.		
1.	I talked to parents who had lost a child.	0.19
10.	I went for counselling.	0.19
18.	I read everything I could find on SIDS.	0.09
29.	I went to the SIDS support group meetings.	0.14
11.	I went to the doctor for information and advice.	0.21
20.	I wanted everybody to know what SIDS is.	0.21
33.	I volunteered.	0.10
31.	I raised money for SIDS.	0.05
32.	I was on the Board of Directors at the SIDS chapter.	0.05
80.	I did in-services for Victims Services.	0.05
79.	I went to national SIDS conferences.	0.05
	Cluster average	0.12
Cluster #2: Finding Out I Am Not Alone.		
19.	I asked the coroner some questions.	0.24
30.	I took the baby sitter to the support group meetings.	0.28
28.	I phoned the SIDS 24 hour line.	0.26
45.	I felt I was not alone after reading about other people's stories.	0.33
43.	I got very emotional hearing stories from new SIDS parents.	0.42
	Cluster average	0.31
Cluster #3: Coming to Terms with the Baby's Death.		
2.	We got help from the minister.	0.65
3.	I talked to my spouse.	0.54
4.	I talked to my spouse's mother.	0.50
5.	I talked to my children.	0.51
22.	We found out what other people had done with the baby's body.	0.43
6.	I got to see my baby.	0.38
26.	We brought the baby's remains home.	0.41
23.	I made the funeral arrangements.	0.41
25.	I went to the funeral.	0.39
27.	When I saw the baby at the funeral, there was something missing.	0.48
69.	I read the sympathy cards.	0.45
	Cluster average	0.47

Table 4 (continued)

Cluster #4: Looking Forward to Another Baby.

7.	I had lots of support from family and friends.	0.85
48.	I became very close to my spouse.	0.96
63.	I know my baby is in heaven.	0.93
50.	I was pregnant again.	0.36
54.	We adopted a baby.	0.50
56.	We cleaned everything in the house before the next baby arrived.	0.57
	Cluster average	0.70

Cluster #5: Doing Normal Things.

9.	I did normal things.	0.42
14.	I kept myself busy.	0.43
65.	I could see babies and not turn away.	0.50
57.	I accepted the situation.	0.49
59.	I know that the baby's death is not anything that people have done.	0.42
17.	I went back to work.	0.44
64.	I had to go on.	0.33
51.	I felt the best thing for me was to have another baby.	0.34
52.	I tried to have another child.	0.34
21.	I found it nice to know that someone else had these feelings and gone on.	0.66
47.	I had to look after my other children.	0.35
	Cluster average	0.43

Cluster #6: Putting It Out of My Mind.

8.	We went away.	0.53
16.	I put it out of my mind.	0.58
15.	I would go out.	0.67
55.	We moved.	0.56
66.	I distanced myself from babies.	0.59
76.	I questioned whether there was something wrong with me when I laughed.	0.82
	Cluster average	0.63

Cluster #7: Questioning Beliefs.

49.	I was relieved to know that my spouse was still grieving and still cared about the baby.	1.00
62.	I asked God's help.	0.70
58.	I had the next baby sleep in our room.	0.78
60.	I blame God.	0.57
61.	I became indifferent to God.	0.49
	Cluster average	0.71

Table 4 (continued)

Cluster #8: Remembering the Baby.

67.	I shared the baby pictures with friends.	0.38
70.	I kept a journal.	0.56
60.	I sent everybody copies of the funeral.	0.32
78.	I find it easier acknowledging that the baby lived.	0.50
71.	I kept a lot of the baby's clothes.	0.22
72.	I looked through the baby's things.	0.22
74.	I try to remember as much as I can.	0.22
75.	I sat in the baby's room.	0.24
73.	I shut the door and left the baby's room as it was.	0.41
	Cluster average	0.34

Cluster #9: Getting Comfort Through Being Alone

12.	I took medications.	0.41
13.	I was hospitalized.	0.38
46.	I wanted the children to leave me alone.	0.39
53.	You know in your mind that you are still a mother but physically there is no baby.	0.34
24.	I asked "Why had this happened?"	0.61
77.	I check my children and my husband when sleeping.	0.77
	Cluster average	0.48

Cluster #10: Being Sad, Angry and Grieving.

34.	I was very angry.	0.06
35.	I cried.	0.00
36.	I had a lot of guilt.	0.00
38.	I was devastated.	0.00
37.	I would get depressed.	0.00
42.	I was hurting.	0.00
40.	I was overwhelmed with grief.	0.01
41.	I felt very lonely.	0.03
39.	I blanked out major blocks of time.	0.24
44.	I cried and wondered if it was a baby when I heard sirens.	0.16
	Cluster average	0.05

Table 5

Cluster items and bridging indices for ten solution concept map for fathers whose babies died from SIDS.

		Bridging index
Cluster #1: Talking.		
1.	I talked to friends at work.	0.00
3.	I talked to people.	0.00
4.	I talked to a relative.	0.00
16.	We called family and friends.	0.04
2.	I did a lot of talking about it.	0.11
5.	I talked to others who understand because they have lost a child.	0.02
6.	I talked to my spouse.	0.06
18.	We went away with my spouses relatives.	0.23
61.	I turned first to the minister.	0.47
63.	I phoned the SIDS help line.	0.31
59.	I organized the 24 hour SIDS line.	0.30
60.	I run as many parent support groups as I can make.	0.41
	Cluster average	0.16
Cluster #2: Getting Support from Others.		
17.	I had support of family and friends.	0.28
62.	I found the SIDS group very helpful.	0.41
64.	Knowing that others have lived through the experience makes you see that you can live.	0.55
39.	I became closer to my spouse.	0.86
67.	I found the emergency response team very sympathetic, helpful, and protective.	0.87
	Cluster average	0.59
Cluster #3: Trying Not to Think About It.		
10.	I exercised or did physical work.	0.73
13.	I spent a lot of time playing the piano.	0.73
12.	I worked to keep my mind from thinking about it.	0.76
11.	I did a lot of day dreaming and thinking about it.	0.76
74.	I couldn't understand, the world wasn't stopping, mine had.	0.80
	Cluster average	0.75

Table 5 (continued)

Cluster #4: Seeking Comfort and Understanding.

15.	I prayed a lot.	0.61
37.	I gave my spouse a hug.	0.77
48.	We began to go to church.	0.51
66.	I asked questions at the SIDS meetings.	0.42
68.	I watched films about SIDS.	0.42
38.	I helped my spouse get over it.	0.59
47.	I said "God, you've always said that you'll be there for us.	0.60
65.	I needed to understand.	0.70
51.	I thought God never figured I was a good enough parent so he took my baby away from me.	0.82
52.	We asked "Why did a little baby go?"	0.72
	Cluster average	0.62

Cluster #5: Distancing.

7.	I did not talk that much to my spouse.	0.65
46.	I said to hell with religion.	0.80
50.	I thought I wouldn't be lucky enough to have children after the baby died.	0.73
21.	We kept the baby's door shut.	0.77
41.	I had to look after the older children.	0.72
43.	We had a new baby.	0.83
	Cluster average	0.75

Cluster #6: Feeling Fear and Helplessness.

8.	I don't talk about it a lot.	0.63
40.	I felt helpless to help my spouse.	0.59
72.	I would wake up at night and check that my wife was breathing.	0.41
23.	I didn't go to the cremation.	0.90
44.	I found it hard with the next baby.	0.56
69.	I was scared to death to see my friend's baby.	0.72
45.	I was afraid that the same thing would happen to our next baby.	0.58
70.	I checked the next baby three or four times during the night.	0.53
71.	The first thing I do when I come home or wake up is check the children.	0.46
	Cluster average	0.60

Table 5 (continued)

Cluster #7: Being Sad and Depressed.

9.	I drank more after the baby died.	0.52
36.	I fought with my spouse.	0.57
14.	I didn't work any more.	0.40
75.	I had bad dreams.	0.29
19.	I lost track of time.	0.33
28.	I almost had a break down.	0.30
29.	I really felt depressed.	0.20
30.	I felt overwhelming emptiness.	0.20
32.	I had a hard time.	0.21
27.	I cried and cried for a long time.	0.48
33.	Sometimes I really hurt.	0.42
34.	I was angry.	0.41
31.	I was devastated.	0.29
35.	I felt a sense of heaviness.	0.30
	Cluster average	0.35

Cluster #8: Accepting that the Baby Lived and Died.

20.	I visited the grave.	0.98
24.	When I saw the baby laid out, I knew my child was not in that body.	0.83
42.	I always acknowledge the baby as part of the family.	0.76
57.	I think my baby has been spared.	0.77
25.	I was glad when I knew the body was gone.	0.76
	Cluster average	0.82

Cluster #9: Remembering the Baby.

26.	I am happy having the baby's cremated remains in a warm house full of love.	0.44
78.	I remember the last night I spent with my baby.	0.57
49.	I like to think that I do everything in the baby's name.	0.38
76.	I remember the baby's birthday and Christmas.	0.28
73.	I knew the baby we gone.	0.53
	Cluster average	0.44

Table 5 (continued)

Cluster #10: Seeking Closure.

22.	We had a funeral.	0.88
53.	I'll meet my baby in heaven.	0.94
58.	I have a little angel on my shoulder that protects me on bad days.	1.00
54.	I'll know and understand everything when I get to heaven.	0.91
55.	I think that life must go on.	0.71
56.	I believe that there is nothing that we could have done.	0.95
77.	I decided that the quality of life was more important than work.	0.92
	Cluster average	0.90

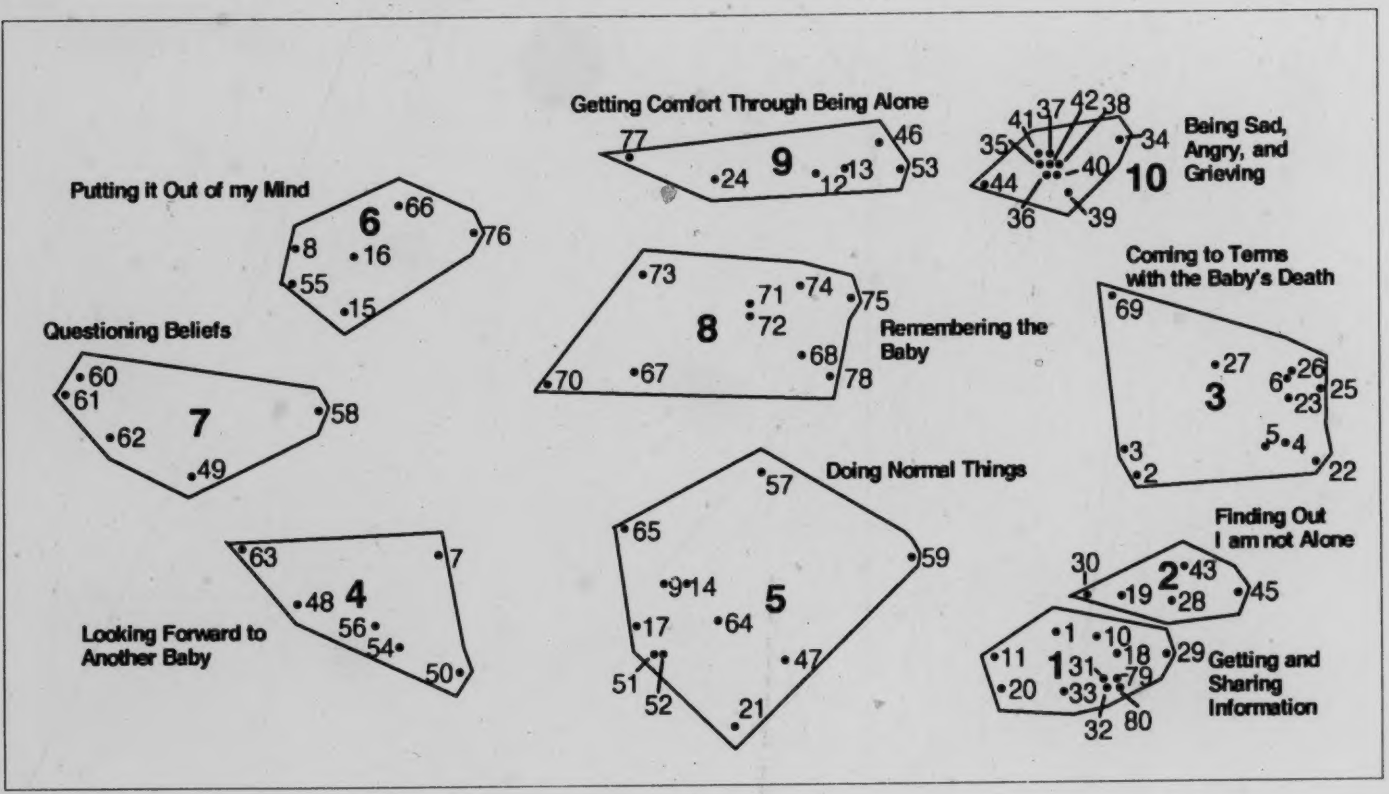
The concept maps for mothers and fathers, each of 10 clusters , are shown in Figures. 3 and 4. The original 80 points of the mothers' point map are shown enclosed by boundaries for 10 clusters. Similarly, the fathers' concept map displays the original 78 points enclosed within 10 clusters. Each cluster contains conceptually similar statements. Clusters on both the mothers' and fathers' concept maps were assigned names. The names were chosen to reflect the theme represented by the statements within each cluster.

Description of the Mothers' Concept Map

While assigning labels to each cluster of both the mothers' and fathers' concept maps was somewhat subjective, the names selected were chosen to describe the theme. The procedure used for naming each cluster involved reviewing the items included in each cluster and those with the low bridging indices were considered to reflect the thematic content of the cluster.

Cluster #1: Getting and Sharing Information

Cluster #1, located at the bottom right side of the map, has a low bridging index indicating this to be a relatively stable cluster. The main theme of this cluster is about acquiring and sharing information. "I went to national SIDS conferences" (#79) suggests exposing oneself to hearing the latest information on SIDS. Other statements included in cluster #1 suggest that mothers may have gained information by their involvement with the CFSID: #29 " I went to the SIDS support group meetings". Statements such as #31 "I raised money for SIDS", #32 "I was on the Board of Directors of the SIDS


Getting Comfort Through Being Alone
Being Sad, Angry, and Grieving
Putting it Out of my Mind
Remembering the Baby
Coming to Terms with the Baby's Death
Questioning Beliefs
Doing Normal Things
Finding Out I am not Alone
Looking Forward to Another Baby
Getting and Sharing Information
1
2
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9
10
77 24 12 13 46 53
41 37 42 38 35 34 44 40 36 39
66 8 16 55 15 76
73 71 74 75 72 68 70 67 78
69 27 6 26 25 23 5 4 3 2 22
60 61 62 58 49
57 65 59 9 14 17 64 47 51 52 21
30 19 43 28 45
1 10 11 18 29 31 79 20 33 32 80
63 7 48 56 54 50

Figure 3
Mothers' concept map: 10 cluster solution.

chapter", #80 "I did in-services for Victims Services", and #33 "I volunteered" indicate a need to be involved in sharing information with others. The need for mothers to be informed is reflected in statements #18 "I read everything I could find on SIDS". Mothers also sought professional help from counselling (#2) and "I talked to parents who had lost a child" #1; these items suggest that information was gained at a more personal level and informally by mothers. The family physician served as a source of support and information (#11, "I went to the doctor for information and advice"). Statement #20, "I wanted everyone to know what SIDS is" indicated the need to educate others.

Cluster #2: Finding Out I am Not Alone

Cluster #2 focuses on finding out that others have experienced a similar tragedy. The closeness of this cluster to cluster #1 is reflected by statements #19, "I asked the coroner some questions" and #30, "I took the babysitter to the support group meetings". While these statements reflect information gathering and sharing of cluster #1, they have been grouped with statements that have the theme of hearing about others in similar circumstances in less structured settings: #28, "I phoned the SIDS 24 hour line"; #45, "I felt I was not alone after reading other people's stories": #43, "I got very emotional hearing stories from new SIDS parents". This cluster suggests a component of emotional support.

Cluster #3: Coming to Terms with the Baby's Death

Items in this cluster reflect coping with practical issues that presented themselves after the baby's death. Understanding that the baby is dead is represented in statements such as "I got to see my baby" (#6), and "When I saw the baby at the funeral, there was something missing" (#27). The sight of the dead baby was confirmation that this terrible event had, in fact, taken place. Even reading the sympathy cards (#69) reinforces the reality of the baby's death. "We found out what other people do with the baby's body" (#22), "I went to the funeral" (#25), "I made the funeral arrangements" (#23), and "We brought the baby's remains home'" (#26) indicated the necessity of dealing with practical issues, such as funeral arrangements which further confirm that the baby is dead. Discussion appeared to be necessary and important in dealing with the baby's death as seen by "I talked to my spouse" (#3), "I talked to my spouse's mother" (#4), "I talked to my children" (#5), and "I got help from the minister" (#2). Talking is necessary for making the practical arrangements, to reach out to others for help and support, and in attempting to make sense of the baby's death.

Cluster #4: Looking Forward to Another Baby

The central theme for this cluster is looking forward, as defined by efforts to have another child. Items "I was pregnant again" (#50), "We adopted a baby" (#54), and "We cleaned everything in the house before the next baby" (#56) reflected efforts to prevent a similar tragedy and move into more comfortable space in their life. The other three items in cluster #4 suggested a sense of comfort that may be necessary in allowing mothers to move forward: "I had lots of support from family and friends" (#7), "I became close to my spouse" (#48), and " I know the baby is in heaven " (#63).

Cluster #5: Doing Normal Things

In the wake of tragedy, doing normal every day things is necessary for survival and for moving through grief. After a death, the reality that life continues for those left behind is represented in items #64 "I had to go on" and #47, "I had to look after my other children". Two items in cluster #5 reflected the need for another baby: "I felt the best thing for me was to have another baby" (#51), and "I tried to have another child" (#52). This desire for another baby may also be seen as an attempt to normalize life. Eventually these mothers put some normalcy into their lives: "I did normal things" (#9), "I kept myself busy" (#14), and "I went back to work" (#17). Mothers also expressed acceptance of their situation in statements such as "I accepted the situation" (#57), "I know that the baby's death is not anything that people have done" (#59), and "I could see babies and not turn away" (#65). Statement #21, "I found it nice to know that someone else had these feelings and had gone on" is a way of making their situation and feelings normal because others had felt the same.

Cluster #6: Putting it Out of My Mind

The theme in cluster #6 is about the mothers' distancing themselves from their baby's death. Statements such as "We went away" (#8), "I would go out" (#15), "We moved" (#55), and "I distanced myself from babies" (#66) indicated actual physical distancing from the reminders of the baby's death. Statements such as "I put it out of my mind" (#16) and "I questioned whether there was something wrong with me when I laughed" (#76) indicated efforts to psychologically distance themselves from memories of the baby's death.

When efforts to gain physical and mental distance were successful, mothers may have been uncomfortable with this success, as reflected by this latter statement.

Cluster #7: Questioning Beliefs

Three items out of the total of five in this cluster reflected mothers' religious feelings. A range of views are expressed from blame, through indifference, to belief: "I blame God" (#60), "I became indifferent to God" (#61), and "I asked God's Help" (#62). These statements suggest mothers' existential uncertainty about God and the nature of the universe; they are questioning beliefs that previously were certain. The statements #58, "I had the next baby sleep in our room" and #49, "I was relieved to know my spouse was still grieving and still cared about the baby" represented the mothers anxiety or practical uncertainty over the well-being of the baby and/or their spouse. Usually, for healthy family members, well-being is accepted without question, and caring may be seen from interaction between child and parent.

Cluster #8: Remembering the Baby

Cluster 8 is located at the centre of the concept map. Four items in this cluster indicated the mothers' need to maintain closeness to their dead baby. This closeness is expressed in the statements "I kept a lot of the baby's clothes" (#71), "I looked through the baby's things" (#72), "I try to remember as much as I can" (#74), and "I sat in the baby's room" (#75). A desire for other people to remember the baby is reflected in "I shared the baby pictures with friends" (#67) and "I sent everybody copies of the funeral service" (#60). The two statements "I shut the door and left the baby's room as it was" (#73) and "I find it easier to acknowledge that the baby lived" (#78) expressed the mothers' need to hold on to something tangible that endorsed that the baby really existed. It may also suggest the need to hold on to something for fear they may forget. While statement #70, "I kept a journal", appears to fit less well, it too may be a way for mothers to make their baby, who has become intangible in death, more real by their writing. Writing in a journal may capture the mothers' feelings and thoughts; these too become memories.

Cluster #9: Getting Comfort Through Being Alone

In cluster #9, the statements suggest that the mothers need to separate themselves from their 'worlds' to cope with the pain of their babies' deaths. Statements such as "I wanted the children to leave me alone" (#46) and "I was hospitalized" (#13) indicate the need for mothers to find some space for themselves away from their families. The search for mental or emotional understanding or peace is expressed in "You know in your mind that you are still a mother but physically there is no baby" (#53). For some, "I took medications "(#12) reflects that the pain of the baby's death was beyond the mother's own coping resources and she required help. These statements all reflect that mothers required to be temporarily removed from their 'worlds' to have time alone or to have help from other sources to deal with their pain. Two items, "I asked 'why had this happened?'" (#24) and "I checked my children and husband when sleeping" (#77) reflect a need to reduce anxiety. Trying to get answers to "Why" is usually a very personal search that may make the mother feel alone. Checking family members during the night is an activity done alone and may create the feeling that she is the only mother that does so.

Cluster #10: Being Sad, Angry, and Grieving

Cluster #10 focuses on the pain and suffering experienced by mothers whose baby died. Statements such as "I was devastated" (#38), "I was hurting" (#42), and "I was overwhelmed with grief" (#40) reflect the depth and extent of mothers' pain. Mothers responded to their loss with certain behaviors recognised as grief: "I cried" (#35), "I had a lot of guilt" (#36), and "I got depressed" (#37). The death of a loved baby in whom mothers invested much time and care leaves a tremendous space ("I felt very lonely" (#41)) and much anger ("I was very angry" (#34)). Although continuing with normal activities, mothers' feelings of sadness and loss are easily triggered by things in their environment bringing back memories, as in "I cried and wondered if it was a baby when I heard sirens" (#44). The pain was so severe that dissociation helped mothers to cope as stated in "I blanked out major blocks of time" (#39).

Description of the Fathers' Concept Map

The procedure for assigning names to each of the ten clusters of the fathers' concept map was identical to that used for the mothers'. The content of the statements with low bridging indices, in conjunction with the content of the majority of statements in a cluster, were used to arrive at a name.

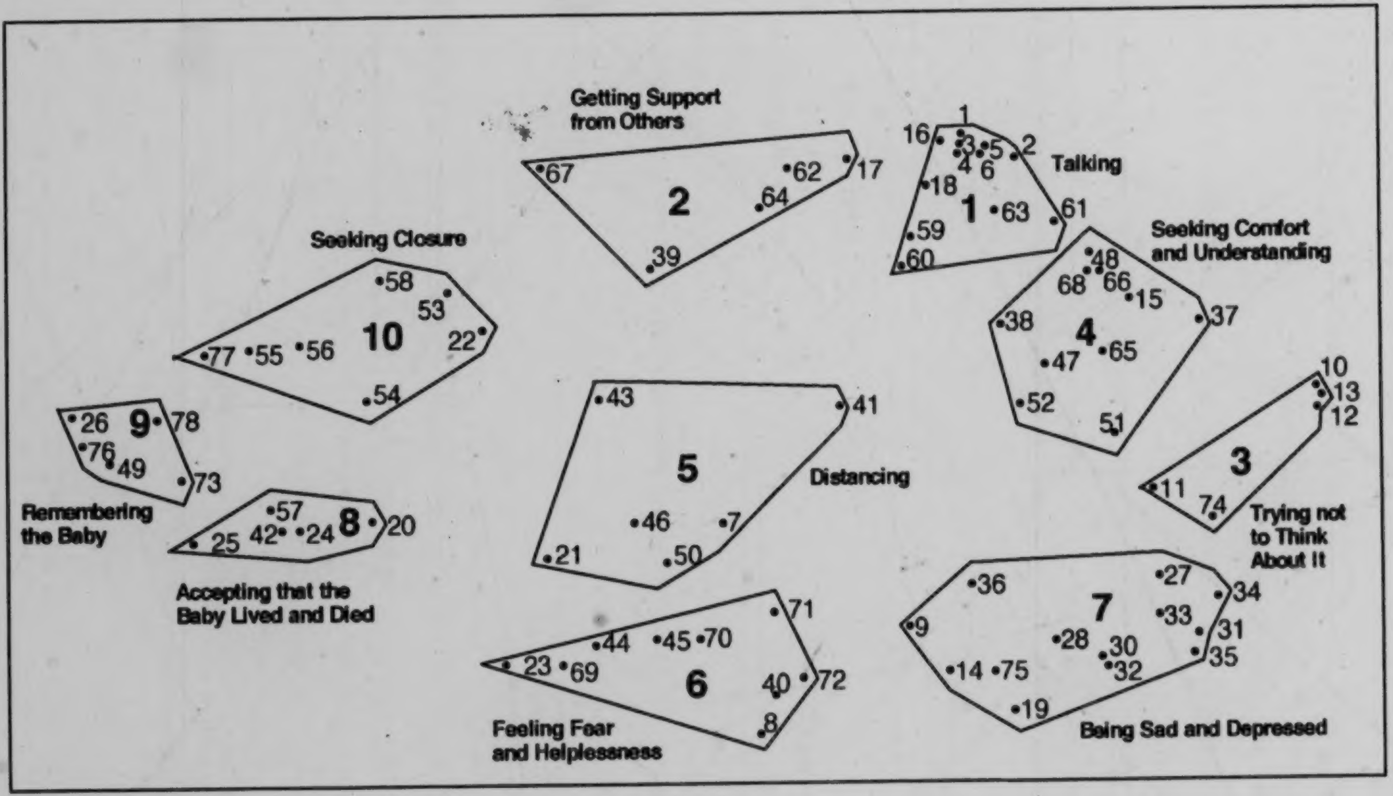
Getting Support from Others
2
67
62
17
64
39
Talking
1
16
3
5
2
4
6
18
63
61
59
60
Seeking Closure
10
58
53
22
77
55
56
54
Seeking Comfort and Understanding
4
48
68
66
15
37
38
47
65
52
51
Remembering the Baby
9
26
78
76
49
73
5
43
41
46
7
21
50
Distancing
3
10
13
12
11
74
Trying not to Think About It
Accepting that the Baby Lived and Died
8
57
25
42
24
20
6
71
44
45
70
23
69
40
72
8
Feeling Fear and Helplessness
7
36
27
34
9
33
31
35
28
30
32
14
75
19
Being Sad and Depressed

Figure 4
Fathers' concept map: 10 cluster solution.

Cluster #1: Talking

Cluster #1 of the fathers' concept map is the most stable of the clusters and reflects the theme of talking. Talking helps in making practical arrangements that are necessary when a baby dies, may be a way to communicate feelings, and sharing the story may help in trying to make sense of a meaningless situation. Fathers expressed their need to talk with others by items such as "I talked to friends at work" (#1), "I talked to a relative" (#4), "I talked to people" (#3), "We called family and friends" (#16), and "I talked to my spouse" (#6). While these previous statements reflect talking to specific individuals, the statement #2 "I did a lot of talking about it" suggests the overall importance of talking in dealing with the baby's death. "I talked to others who understand because they have lost a baby" #5 indicates the need to talk at a personal level in order to gain emotional support. The statement "We went away with my spouse's relatives" (#18) may also reflect the need to spend time with people to whom they can talk comfortably. Statements such as "I turned first to the minister" (#61), and "I phoned the SIDS help line" (#63) indicated that fathers sought help and support from others outside their immediate family. A need to provide support to others through talking is expressed in fathers' statements "I organized the 24 hour SIDS line" (#59) and "I run as many parent support groups as I can make" (#60).

Cluster #2: Getting Support from Others

The main theme in cluster #2 is that of fathers gaining emotional support from other people: "I had support of family and friends" (#17), and "I found the SIDS line very helpful" (#62). "Knowing that others had lived through the experience makes you see that you can live" (#64) appears to be a statement reflecting understanding and hope from others who have experienced a similar tragedy. Emotional support brings feelings of comfort; understanding your spouse in different ways may increase the emotional bond as suggested by "I became closer to my spouse" (#39). Help from professionals who understand the sensitive nature of parents' feelings when a baby dies is very important and helpful: "I found the emergency response team very sympathetic, helpful, and protective" (#67).

Cluster # 3: Trying Not to Think About It

The items in this cluster reflected that fathers coped by keeping busy or putting the death of their baby out of their minds. Busy activity can be very personal for each individual as represented by the following statements:"I exercised or did physical work" (#10), "I spent a lot of time playing the piano" (#13), and "I worked to keep my mind from thinking about it" (#12). Other ways to clear the mind of painful thoughts are to be in a trance-like state as suggested by "I did a lot of day dreaming and thinking" (#11) or to try and make sense of what has happened as expressed in "I could not understand, the world was not stopping, mine had" (#74). The latter statement creates the sense of being suspended in another place or time so removing the father from the pain of the present.

Cluster #4: Seeking Comfort and Understanding

The theme of cluster #4, making sense of what has happened, is closely related to achieving comfort. Statements that reflected fathers' coping by wanting to understand what had happened to their baby are "I asked questions at meetings" (#66) and "I watched films about SIDS" (#68) and "I needed to understand" (#65). "We began to go to church" (#48) and "I helped my spouse get over it" (#38) are statements that reflect fathers becoming active in trying to deal with their situation. Both statements suggest that fathers need to be actively involved in helping themselves either by seeking help or providing help. "I prayed a lot" (#15), and "I said 'God, you've always been there for us'" (#47) indicated that fathers sought comfort in religious beliefs or affiliations. Making existential sense of the baby's death played a role in fathers' coping: "We asked 'why did a little baby go?'" (#52) and "I thought God never figured I was good enough parent so he took my baby away from me" (#51). Being in a relationship with their spouses also brought fathers comfort, comfort which was gained by physical closeness to their spouse ("I gave my spouse a hug" (#37)).

Cluster #5: Distancing

The theme in cluster 5, which is located at the centre of the fathers' concept map, is one of making changes that reflect attempts to bring closure to the death of the baby or attempts to move their life forward. Some statements reflect changes in the fathers' behavior that put distance between themselves and their spouses ("I did not talk to my spouse" [#7]), distance between their previous beliefs that no longer seemed to apply ("I said hell to religion" [#46]), and attempts to place barriers between the past and the present ("We kept the baby's door closed after the baby died" [#21]). Moving into the future was a helpful coping strategy that put distance between the past and the present. Some statements such as "I had to look after the older children" (#41), "I thought I would not be lucky enough to have children after the baby died."(#50), and "We had a new baby" (#43) distance the fathers from the painful time of their babies' deaths by moving them into more normal aspects of living.

Cluster #6: Feeling Fear and Helplessness

Statements in this cluster expressed fathers' fears, anxiety and feelings of helplessness. Fathers described behaviors that reflected their fears for the safety of their family members: "I checked the next baby three or four times through the night" (#70), " The first thing I do when I come home or waken up is check the children" (#71), "I would wake up at night and check that my wife was breathing" (#72), and "I found it hard with the next baby"(#44). "I was afraid that the same thing would happen to our next baby"(#45) indicates an expectation that something bad will happen again. Fathers' perceptions of anxiety and lack of control is obvious in the statement "I felt helpless to help my spouse" (#40). "I was scared to death to see my friend's baby" (#69), and statement #23, "I did not go to the cremation" suggests the belief that by not doing something, pain or anxiety may be avoided. "I don't talk about it a lot" (#8) also suggests a fear of being in contact with the pain and loss. These statements suggest that fathers fear possible associations with the baby will be too difficult for them.

Cluster #7: Being Sad and Depressed

Cluster #7 represents fathers' emotional pain and their efforts to cope with it. Statements such "I really felt depressed" (#29), "I felt overwhelming emptiness" (#30), and "I had a hard time" (#32) indicate the emptiness and the lack of meaning to life fathers suffered in coping with their babies' deaths. "I felt devastated" (#31), "I felt a sense of heaviness" (#35), and "I almost had a break down" (#28) suggest the depth and extent of their pain being almost unbearable. Fathers' pain and sadness is expressed in statements such as "Sometimes I really hurt" (#33), and "I cried and cried for a long time" (#27). The majority of the statements in this cluster represent a period that is devoid of joy and purpose. Some of these joyless statements described fathers having dissociative or post traumatic experiences: "I lost track of time" (#19), "I had bad dreams" (#75). Anger accompanying grief is described by fathers' statements #36 and #34 ("I fought with my wife" and "I was very angry"). Sadness and depression to the point of being unable to cope is suggested by the statement "I didn't work any more" (#14). The statement, "I drank more after the baby died" (#9) indicated coping with the loss and feelings of depression by self medication.

Cluster #8: Accepting that the Baby Lived and Died

The theme in cluster #8 reflects fathers coping with the reality of their child's death: "I was glad when I knew the body had gone" (#25), "When I saw the baby laid out, I knew my child was not in that body" (#24), and "I visited the grave" (#20). Attempts to make sense of the baby's death is suggested by "I think my baby has been spared" (#57). While accepting that the baby is dead, fathers also needed to acknowledge the baby's existence: "I always acknowledge the baby as part of the family" (#42).

Cluster #9: Remembering the Baby

The theme of cluster #9 is about remembering the baby. Fathers remember by acknowledging the baby lived, "I remember the baby's birthday and Christmas" (#76). Another way that fathers described remembering their child is by honouring them, as in "I like to think I do everything in the baby's name" (#49). Fathers also remembered time spent with their baby: "I remember the last night I spent with my baby"(#78). Statement #26, "I am happy having the baby's cremated remains in a warm house full of love" (#26) describes the need to have the baby close and safe, which may be a way of remembering.

Cluster #10: Seeking Closure

The theme expressed in this cluster is eventual acceptance and continuing with living. "We had a funeral" (#22) is a statement that reflects one of the oldest and most basic ways of coping with death. Although fathers struggled with making sense of their child's death ("I'll know and understand everything when I get to heaven" (#54)), they described trying to find comfort in beliefs such as "I'll meet my baby in heaven" (#53). These beliefs also helped in daily living, as expressed by "I have a little angel on my shoulder that protects me on bad days" (#58). "I think life must go on" (#55) and "I decided that the quality of life was more important than work" (#77) indicated that fathers needed to move into the future but perhaps with changed priorities. Fathers needed to know that they were not responsible: "I believe that there is nothing that we could have done" (#56).

Prevalence of Themes for Mothers and Fathers

Concept mapping does not in itself provide any data on the prevalence of a given experience or theme among participants. However, examination of how many participants reported using the certain items within each cluster provides some evidence of how widespread the themes and the experiences which comprise those themes are. This information was derived by comparing the content of original statements by participants (Appendix I for mothers and Appendix J for fathers) to the content of statements in each cluster for the mothers' and fathers' concept maps. As may be seen in Table 6, the proportion of mothers who reported using one or more items within a cluster ranged from a high of 83.3 % to a low of 33.3 %; 7 out of ten clusters were endorsed by 50 % or more mothers. As may be seen in Table 7, the proportion of fathers who reported using one or more items within a cluster ranged from a high of 63.6 % to a low of 27.3 %; 5 out of ten clusters were endorsed by 50 % or more fathers. In short, there is reason to believe that the concept maps depict experiences that are not limited to one or two isolated individuals.

Table 6

Distribution of mothers' endorsements of statements for each cluster.

Theme	Mother participants											
	1	2	3	4	5	6	7	8	9	10	11	12
Cluster #1: Getting and Sharing Information.												
1. I talked to parents who had lost a child.	X	X						X				X
10. I went for counselling.			X		X	X						
18. I read everything I could find on SIDS.	X	X			X		X	X				X
29. I went to the SIDS support group meetings.	X	X	X		X	X	X	X		X	X	X
11. I went to the doctor for information and advice.	X				X			X				
20. I wanted everybody to know what SIDS is.	X	X				X		X				
33. I volunteered.		X										
31. I raised money for SIDS.	X		X									
32. I was on the Board of Directors at the SIDS chapter.	X					X		X				
80. I did in-services for Victims Services.	X											
79. I went to national SIDS conferences.	X											
Total number of statements reported	9	5	3	0	4	4	2	6	0	1	1	3

Total number mothers represented in cluster #1 = 10

Theme	1	2	3	4	5	6	7	8	9	10	11	12
Cluster #2: Finding out I am not Alone.												
19. I asked the coroner some questions.	X											
30. I took the baby sitter to the support group meetings.	X							X			X	
28. I phoned the SIDS 24 hour line.	X	X									X	
45. I felt I was not alone after reading about other people's stories.		X										
43. I got very emotional hearing stories from new SIDS parents.		X										
Total number of statements reported	3	3	0	0	0	0	0	1	0	0	2	0

Total number of mothers represented in cluster #2 = 4

Table 6 (continued)

Theme	Mother participants											
	1	2	3	4	5	6	7	8	9	10	11	12
Cluster #3: Coming to Terms with the Baby's Death.												
2. We got help from the minister.	X	X										
3. I talked to my spouse.	X	X					X	X				
4. I talked to my spouse's mother.		X										
5. I talked to my children.								X	[X]			
22. We found out what other people had done with the baby's body.	X											
6. I got to see my baby.	X			X								
26. We brought the baby's remains home.	X											
23. I made the funeral arrangements.		X						X				
25. I went to the funeral.		X		X		X		X	X			
27. When I saw the baby at the funeral, there was something missing.	X								X			
69. I read the sympathy cards.		X										
Total number of statements reported	6	6	0	2	0	1	1	4	3	0	0	0
Total number of mothers represented in cluster #3 =7												
Cluster #4: Looking Forward to a new Baby												
7. I had lots of support from family and friends.	X			X	X	X			X	X	X	
48. I became very close to my spouse.		[X]			X							
63. I know my baby is in heaven.	X											
50. I was pregnant again.	X	X				X		X				
54. We adopted a baby.									X			
56. We cleaned everything in the house before the next baby arrived.						X						
Total number of statements reported	3	2	0	1	2	3	0	1	2	1	1	
Total number of mothers represented in cluster #4 = 9												

Table 6 (continued)

Theme	Mother participants											
	1	2	3	4	5	6	7	8	9	10	11	12
Cluster #5: Doing Normal Things												
9. I did normal things.						X	X					
14. I kept myself busy.	X	X			X	X						
65. I could see babies and not turn away.	X						X					
57. I accepted the situation.							X					
59. I know that the baby's death is not anything that people have done.	X	X				X						
17. I went back to work.		X			[X]	X		X				
64. I had to go on.		X			X		X					
51. I felt the best thing for me was to have another baby.		X				X						
52. I tried to have another child.			X									
21. I found it nice to know that someone else had these feelings and gone on.			X									
47. I had to look after my other children.			X									
Total number of statements reported	3	5	3	0	3	5	4	1	0	0	0	0

Total number of mothers represented in cluster #5 =7

Theme	1	2	3	4	5	6	7	8	9	10	11	12
Cluster #6: Putting it out of my Mind.												
8. We went away.						X						
16. I put it out of my mind.		X										
15. I would go out.		X										
55. We moved.	X	X										
66. I distanced myself from babies.		X										
76. I questioned whether there was something wrong with me when I laughed.						X		X				
Total number of statements reported	1	4	0	0	0	2	0	1	0	0	0	0

Total number of mothers represented in cluster #6 = 4

Table 6 (continued)

Theme	Mother participants											
	1	2	3	4	5	6	7	8	9	10	11	12
Cluster #7: Questioning Beliefs.												
49. I was relieved to know that my spouse was still grieving and still cared about the baby.									X			
62. I asked God's help.									X	X		
58. I had the next baby sleep in ourroom.						X						
60. I blame God.	X											
61. I became indifferent to God.		X										
Total number of statements reported	1	1	0	0	0	1	0	0	2	1	0	0
Total number of mothers represented in cluster #7 = 5												
Cluster #8: Remembering the Baby.												
67. I shared the baby pictures with friends.	X		X					X	X			
70. I kept a journal.	X	X										
60. I sent everybody copies of the funeral.	X											
78. I find it easier acknowledging that the baby lived.		X										
71. I kept a lot of the baby's clothes.	X	X										
72. I looked through the baby's things.	X	X										
74. I try to remember as much as I can.		X		X								
75. I sat in the baby's room.		X										
73. I shut the door and left the baby's room as it was.		X	X									
Total number of statements reported	5	7	2	1	0	0	0	1	1	0	0	0
Total number of mothers represented in cluster #8 = 6												

Table 6 (continued)

Theme	Mother participants 1	2	3	4	5	6	7	8	9	10	11	12
Cluster #9: Getting Comfort Through Being Alone												
12. I took medications.			X		X							
13. I was hospitalized.			X									
46. I wanted the children to leave me alone.		X										
53. You know in your mind that you are still a mother but physically there is no baby.	X	X										
24. I asked "Why had this happened?"		[X]				X						
77. I check my children and my husband when sleeping.								X				
Total number of statements reported	1	3	2	0	1	1	0	1	0	0	0	0

Total number of mothers represented in cluster #9 = 6

Theme	Mother participants 1	2	3	4	5	6	7	8	9	10	11	12
Cluster #10: Being Sad, Angry and Grieving.												
34. I was very angry.	X	X										
35. I cried.	X					X	X		X			
36. I had a lot of guilt.		X				X						
38. I was devastated.					X	X						
37. I would get depressed.		X										
42. I was hurting.		X										
40. I was overwhelmed with grief.					X	X			X	X		
41. I felt very lonely.		X										
39. I blanked out major blocks of time.						X						
44. I cried and wondered if it was a baby when I heard sirens.								X				
Total number of statements reported	2	5	0	0	2	5	1	1	2	1	0	0

Total number of mothers represented in cluster #10 = 8

[X] = statement deemed to contain similar content

Table 7

Distribution of fathers' endorsements of statements for each cluster.

Theme	Father participants 1	2	3	4	5	6	7	8	9	10	11
Cluster #1: Talking.											
1. I talked to friends at work.	X		X								
3. I talked to people.	X					[X]					X
4. I talked to a relative.	X	X									
16. We called family and friends.		X			X						
2. I did a lot of talking about it.	X				X						
5. I talked to others who understand because they have lost a child.						[X]					
6. I talked to my spouse.	X	X			X	X					
18. We went away with my spouse's relatives.			X								
61. I turned first to the minister.	X										
63. I phoned the SIDS help line.	X	X				X					
59. I organized the 24 hour SIDS line.	X										
60. I run as many parent support groups as I can make.	X										
Total number of statements reported	**9**	**4**	**2**	**0**	**3**	**4**	**0**	**0**	**0**	**0**	**1**
Total number fathers represented in cluster #1 = 6											
Cluster #2: Getting Support from Others.											
17. I had support of family and friends.						X					
62. I found the SIDS line very helpful.	X	X				X	X			X	
64. Knowing that others have lived through the experience makes you see that you can live.						X					
39. I became closer to my spouse.											X
67. I found the emergency response team very sympathetic, helpful, and protective.						X					
Total number of statements reported	**1**	**1**	**0**	**0**	**0**	**4**	**1**	**0**	**0**	**1**	**1**
Total number fathers represented in cluster #2 = 6											

Table 7 (continued)

Theme	Father participants										
	1	2	3	4	5	6	7	8	9	10	11
Cluster #3: Trying not to Think About It											
10. I exercised or did physical work.	X								X		
13. I spent a lot of time playing the piano.									X		
12. I worked to keep my mind from thinking about it.								X		X	
11. I did a lot of day dreaming and thinking about it.	X										
74. I couldn't understand, the world wasn't stopping, mine had.			X								
Total number of statements reported	2	0	1	0	0	0	0	1	2	1	0

Total number fathers represented in cluster #3 = 5

Theme	Father participants										
	1	2	3	4	5	6	7	8	9	10	11
Cluster #4: Seeking Comfort and Understanding											
15. I prayed a lot.					X						
37. I gave my spouse a hug.	X										
48. We began to go to church.							X				
66. I asked questions at the SIDS meetings.						X					
68. I watched films about SIDS.						X					
38. I helped my spouse get over it.								X			
47. I said "God, you've always said that you'll be there for us.					X						
65. I needed to understand.						X					
51. I thought God never figured I was a good enough parent so he took my baby away from me.	X										
52. We asked "Why did a little baby go?"	[X]	X					X				
Total number of statements reported	3	1	0	0	2	3	2	1	0	0	0

Total number fathers represented in cluster #4 = 6

Table 7 (continued)

Theme	Father participants										
	1	2	3	4	5	6	7	8	9	10	11
Cluster #5: Distancing											
7. I did not talk that much to my spouse.	X										
46. I said to hell with religion.	X										
50. I thought I wouldn't be lucky enough to have children after the baby died.	X										
21. We kept the baby's door shut.			X								
41. I had to look after the older children.		X				X				X	
43. We had a new baby.	X	X	X								
Total number of statements reported	4	2	2	0	0	1	0	0	0	1	0
Total number fathers represented in cluster #5 = 5											
Cluster #6: Feeling Fear and Helplessness											
8. I don't talk about it a lot.			X								
40. I felt helpless to help my spouse.	X										
72. I would wake up at night and check that my wife was breathing.											X
23. I didn't go to the cremation.	X										
44. I found it hard with the next baby.			X								
69. I was scared to death to see my friend's baby.	X										
45. I was afraid that the same thing would happen to our next baby.						X					
70. I checked the next baby three or four times during the night.	X					X					
71. The first thing I do when I come home or wake up is check the children.						X					
Total number of statements reported	4	0	2	0	0	3	0	0	0	0	1
Total number fathers represented in cluster #6 = 4											

Table 7 (continued)

Theme	Father participants										
	1	2	3	4	5	6	7	8	9	10	11
Cluster #7: Being Sad and Depressed											
9. I drank more after the baby died.	X										
36. I fought with my spouse.	X										
14. I didn't work any more.			X								
75. I had bad dreams.			X								
19. I lost track of time.		X									
28. I almost had a break down.		X									
29. I really felt depressed.	X			X							
30. I felt overwhelming emptiness.			X						X		
32. I had a hard time.			X	X							
27. I cried and cried fro a long time.	X	X				X					
33. Sometimes I really hurt.	X	X	X								
34. I was angry.	X								X		X
31. I was devastated.	X										
35. I felt a sense of heaviness.									X		
Total number of statements reported	7	4	5	2	0	1	0	0	3	0	1

Total number fathers represented in cluster #7 = 7

Theme	1	2	3	4	5	6	7	8	9	10	11
Cluster #8: Accepting that the Baby Lived and Died.											
20. I visited the grave.		X			X						
24. When I saw the baby laid out, I knew my child was not in that body.	X				X						
42. I always acknowledge the baby as part of the family.					X	X					
57. I think my baby has been spared.					X				X		
25. I was glad when I knew the body was gone.	X										
Total number of statements reported	2	1	0	0	4	1	0	0	1	0	0

Total number fathers represented in cluster #8 = 5

Table 7 (continued)

Theme	Father participants										
	1	2	3	4	5	6	7	8	9	10	11
Cluster #9: Remembering the Baby.											
26. I am happy having the baby's cremated remains in a warm house full of love.	X										
78. I remember the last night I spent with my baby.					X						
49. I like to think that I do everything in the baby's name.	X										
76. I remember the baby's birthday and Christmas.			X								
73. I knew the baby we gone.			X								
Total number of statements reported	2	0	2	0	1	0	0	0	0	0	0

Total number fathers represented in cluster #9 = 3

Theme	1	2	3	4	5	6	7	8	9	10	11
Cluster #10: Seeking Closure.											
22. We had a funeral.	X										
53. I'll meet my baby in heaven.	X										
58. I have a little angel on my shoulder that protects me on bad days.	X										
54. I'll know and understand everything when I get to heaven.	X										
55. I think that life must go on.						X		X	X	X	
56. I believe that there is nothing that we could have done.						X				X	
77. I decided that the quality of life was more important than work.				X	X						
Total number of statements reported	4	0	0	1	1	2	0	1	1	2	0

Total number fathers represented in cluster #10 = 7

[X] = statement deemed to contain similar content

Part Two: Gender Comparison

Differences and similarities in ways of responding between mothers and fathers whose babies died from SIDS was investigated by comparing 1) statements on the master lists, 2) frequency of use of statements, and 3) concept maps.

Statement Similarities/Differences

Mothers' and fathers' statements that represented the same ways of responding were placed opposite each other as shown in Table 8. Some statements that were deemed to be similar ways of responding were placed in a grouping together. The percentage of statements that were shared by mothers and fathers was determined by the following equation:

$$\frac{\text{No. of shared female statements + No. of shared male statements X 100 \%}}{\text{Total no. female statements + Total no. male statements}}$$

The majority of the statements (70%) were deemed by a group of judges to express the same or similar ways of responding for the mothers and the fathers.

Mothers and fathers reported using similar ways of responding: talking, getting support from others, having another baby, feeling anxious about the new baby and other family members, accepting that they did not cause the baby's death, believing that life goes on, and questioning their current religious beliefs. Both parents experienced sadness and depressive symptoms after the baby's death. Having a funeral, keeping busy and returning to work were shared parental ways of coping. The baby's death

Table 8

Comparison of statements generated by mothers and fathers.

No.	Mothers	No.	Fathers
1	I talked to parents who had lost a child.	5	I talked to others who understand because they have lost a baby.
2	We got help from the minister.	61	I turned first to the minister.
3 4 5	I talked to my spouse. I talked to my spouse's mother. I talked to my children.	6 7 4 1 3 2 8	I talked to my spouse. I did not talk much to my spouse. I talked to a relative. I talked to friends at work. I talked to people. I did a lot of talking. I do not talk about it a lot
6	I got to see my baby.		
7	I had lots of support from family and friends.	17	I had support from family and friends.
		16	We called family and friends.
8	We went away.	18	We went away with my spouse's relatives.
9 17	I did normal things. I went back to work.		
		14	I didn't work any more.
10	I went for counselling.		
11 19	I went to the doctor for information and advice. I asked the coroner some questions.		
12	I took medications.		
		9	I drank more after the baby died.
13	I was hospitalized.		

Table 8 (continued)

No.	Mothers	No.	Fathers
14 15	I kept myself busy. I would go out.	10 13	I exercised or did physical work. I spent a great deal of the time playing the piano.
16	I put it out of my mind.	12	I worked to keep my mind from thinking about it.
18 79	I read everything I could find on SIDS. I went to national SIDS conferences.	68 66	I watched films about SIDS. I asked questions at the SIDS meetings.
20	I wanted everybody to know what SIDS is.		
21	I found it nice to know that someone else had these feelings and had gone on.	64	Knowing others have lived through this experience makes you see that you can live.
23 22	I made the funeral arrangements. We found out what other people did with the baby's body.		
25	I went to the funeral.	22	We had a funeral.
27	When I saw the baby at the funereal, there was something missing.	24	When I saw the baby laid out I knew my child was not in that body.
26	We brought the baby's remains home.	26	I am happy having the baby's cremated remains in a warm house full of love.
		73	I knew the baby was gone.
24	I asked "Why had this happened?"	65 52 54	I needed to understand. We asked "Why did a little baby go?" I'll know and understand everything when I get to heaven.
28 29 30	I phoned the SIDS 24 hour line. I went to the SIDS support group meetings. I took the baby sitter to the support group meetings.	63 62	I phoned the SIDS help line. I found the SIDS group very helpful.
31 32 33 80	I raised money for SIDS. I was on the Board of Directors of the SIDS chapter. I volunteered. I did in-services for Victim Services.	59 60	I organised the 24 hour SIDS line. I run as many parent support groups as I can make.
39	I blanked out major blocks of time.	19	I lost track of time.

Table 8 (continued)

No.	Mothers	No.	Fathers
		11	I did a lot of daydreaming and thinking.
		74	I could not understand, the world was stopping, mine had.
34	I was very angry.	34	I was angry.
35	I cried.	27	I cried and cried for a long time.
42	I was hurting.	33	Sometimes I really hurt.
37	I would get depressed.	29	I really felt depressed.
38	I was devastated.	31	I was devastated.
		28	I almost had a break down.
		35	I felt a sense of heaviness.
40	I was overwhelmed with grief.	32	I had a hard time.
41	I felt very lonely and empty.	30	I felt overwhelming emptiness.
36	I had a lot of guilt.		
43	I got very emotional hearing stories from new SIDS parents.		
44	I cried and wondered if it was a baby when I heard sirens.		
45	I felt I was not alone after reading other people's stories.		
46	I wanted my children to leave me alone.		
47	I had to look after my other children.	41	I had to look after the older children.
48	I became very close to my spouse.	39	I became closer to my spouse.
		36	I fought with my spouse.
		38	I helped my spouse get over it.
		40	I felt helpless to help my spouse.
		37	I gave my spouse a hug.
49	I was relieved to know that my spouse was still grieving and still cared about the baby.		

Table 8 (continued)

No.	Mothers	No.	Fathers
50	I was pregnant again.	43	We had a new baby.
51	I felt the best thing for me was to have a baby.		
52	I tried to have another child.		
54	We adopted a baby.		
		50	I thought I would not be lucky enough to have children after the baby died.
56	We cleaned everything in the house before the next baby arrived.		
58	I had the next baby sleep in our room.		
77	I check my children and my husband when sleeping.	70	I checked the next baby 3-4 times during the night.
		71	The first thing I do when I come home or wake up is to check the children.
		72	I would wake up at night and check that my wife was breathing.
		44	I found it hard with the new baby.
		45	I was afraid the same thing would happen to our next baby.
57	I accepted the situation.		
59	I know that the baby's death is not anything that people have done.	56	I believe that there is nothing that we could have done.
64	I had to go on.	55	I think that life must go on.
		77	I decided that the quality of life was more important than work.
60	I blame God.	51	I thought God never figured I was a good enough parent so he took my baby away from me.
61	I became indifferent to God.	46	I said to hell with religion.
62	I asked God's help.	47	I said "God you've always said that you'll be there for us."
		15	I prayed a lot.
		48	I began to go to church.

Table 8 (continued)

No.	Mothers	No.	Fathers
63	I know the baby is in heaven.	53	I will meet my baby in heaven.
66	I distance myself from babies.	69	I was scared to death to see my friend's baby.
65	I could see babies and not turn away.		
67 68 69 70	I shared the baby pictures with friends. I sent everybody copies of the funeral. I read the sympathy cards. I kept a journal.		
73	I shut the door and left the baby's room.	21	We kept the baby's door closed.
71 72 75 74	I kept a lot of the baby's clothes. I looked through the baby's things. I sat in the baby's room. I try to remember as much as I can.	49 76	I like to do everything in the baby's name. I remember the baby's birthday and Christmas.
78	I find it easier to acknowledge that the baby lived.	42	I always acknowledge the baby as part of the family.
		20	I visited the grave.
		23	I did not go to the cremation.
		25	I was glad when I knew the body was gone.
55	We moved.		
		57	I think my baby has been spared.
		58	I have a little angel on my shoulder that protects me on bad days.
		75	I had bad dreams.
		78	I remember the last night I spent with my baby.
76	I questioned whether there was something wrong with me when I laughed.		
53	You know in your mind that you are still a mother but physically there is no baby		
		67	I found the emergency response team very sympathetic, helpful and protective.

made spouses feel closer to one another and they talked to each other. Having other children was also seen as a way of coping because the children needed to be cared for. Mothers and fathers both wanted information about SIDS; they gathered this in different ways with mothers emphasizing reading and fathers in more passive ways such as watching films. Although memories came from different aspects of the baby's life, both mothers and fathers reported remembering the baby. They also tried to make sense of the baby's death by asking "Why" questions. Both parents reported getting help and support from a support group and its resources.

The remaining twenty to thirty percent of the statements that were not deemed to be similar in content reflect a combination of gender or sexual biases and individual differences.

Differences in Mothers' Ways of Responding

Some gender differences for mothers relate to their role as mothers: need to see the baby, questioning their role after the baby died. Mothers reported seeing health professionals for help and described situations where they became very emotional. Sharing memories of the baby and information about SIDS with family and friends was important to mothers. They also reported doing normal things.

Some responses reported by mothers may reflect individual differences between mothers rather than gender biases. Mothers making the funeral arrangements may reflect individual needs or they may have made the arrangements with others but the importance of that ceremony has remained. Two mothers reported moving; this may be gender biased if the mother spends most of her time at home but it may also reflect individual differences. The need to know whether their spouse still cared about the baby, needing to be left alone, and accepting the situation may be individualistic for some mothers.

Differences in Fathers' Ways of Responding

While mothers sought professional help and used medication to deal with the loss, one father resorted to self-medication by drinking alcohol. The traditional male role of family protector is indicated by statements such as "I helped my spouse get over it" (#38) and "I felt helpless to help my spouse" (#40). Accepting the baby's death and then making the best of the situation by a change in priorities may be a male gender bias. Taking charge of the situation may be implicit in the statement "we called family and friends" (#16) but the use of the pronoun 'we' suggests it was a shared task.

A number of the ways of responding reported by fathers appear to reflect individual differences rather than sexual biases: not working any more, daydreaming or the world having stopped, visiting the grave, not attending the cremation, having bad dreams and believing the baby had been spared. One father found help given by the emergency response team to be comforting. Another father remembered the last night spent with the baby. One father gained strength from the almost magical or spiritual belief that he was protected on bad days by an angel. Within the couple relationship, one father reported fighting with and embracing his wife; both actions may occur within a relationship and are dependent upon the individual and the circumstances.

Frequency of Use of Statements

The frequency with which particular statements were reported by mothers and fathers is displayed in Tables 9 and 10. Mothers and fathers both reported a similar range of ways of responding to the death of their babies from SIDS: mothers generated 80 statements and fathers, 78 statements. Examination of the two tables indicates that fathers use the reported statements less frequently than do mothers. A number of statements are endorsed once only on each table indicating that one person contributed that way of responding to the concept mapping procedure.

Mothers

Ten of the twelve participants reported getting support and help from the CFSID support group (83%). Three mothers reported using the SIDS 24 hour help line, another 3 mothers were on the Board of Directors of the local CFSID chapter, and 2 mothers reported raising money for SIDS. Involvement with the CFSID indicates that for mothers this provided support, friendship and perhaps purpose after the deaths of their babies.

Six mothers had support of family and friends; this was the second most reported statement. An extended support system appears to be of major importance to mothers coping with the tragedy of a child's death. Talking was well used by mothers; most frequently mothers reported talking to their spouse (4) and seeking to speak with others who had lost a child (4). Communicating with a spouse may indicate a very personal level of coming

Table 9

Frequency of use of mothers' statements.

	Statements	frequency											
		1	2	3	4	5	6	7	8	9	10	11	12
1	I talked to parents who had lost a child.	X	X	X	X								
2	We got help from the minister.	X	X										
3	I talked to my spouse.	X	X	X	X								
4	I talked to my spouse's mother.	X											
5	I talked to my children.	X	X										
6	I got to see my baby.	X	X										
7	I had lots of support from family and friends.	X	X	X	X	X	X	X					
8	We went away.	X											
9	I did normal things.	X	X										
10	I went for counselling.	X	X	X									
11	I went to the doctor for information and advice.	X	X	X									
12	I took medications.	X	X										
13	I was hospitalised.	X											
14	I kept myself busy.	X	X	X	X								
15	I would go out.	X											
16	I put it out of my mind.	X											
17	I went back to work.	X	X	X	[X]								
18	I read everything I could find on SIDS.	X	X	X	X	X	[X]						
19	I asked the coroner some questions.	X											
20	I wanted everybody to know what SIDS is.	X	X	X	X								
21	I found it nice to know that someone else had these feelings and had goneon.	X											
22	We found out what other people did with the baby's body.	X											
23	I made the funeral arrangements.	X	X										
24	I asked "Why had this happened?"	X	[X]										
25	I went to the funeral.	X	X	X	X	X							
26	We brought the baby's remains home.	X											
27	When I saw the baby at the funeral, there was something missing.	X	X										
28	I phoned the SIDS 24 hour line.	X	X	X									
29	I went to the SIDS support	X	X	X	X	X	X	X	X	X	X		
30	I took the babysitter to the support group meetings.	X	X	[X]									
31	I raised money for SIDS.	X	X										
32	I was on the Board of Directors of the SIDS chapter.	X	X	X									
33	I volunteered.	X											

Table 9 (continued)

	Statements	frequency											
		1	2	3	4	5	6	7	8	9	10	11	12
34	I was very angry.	X	X										
35	I cried.	X	X	X	X								
36	I had a lot of guilt.	X	[X]										
37	I would get depressed.	X											
38	I was devastated.	X	X										
39	I blanked out major blocks of time.	X											
40	I was overwhelmed with grief.	X	X	X	[X]								
41	I felt very lonely and empty.	X											
42	I was hurting.	X											
43	I got very emotional hearing stories from new SIDS parents.	X											
44	I cried and wondered if it was a baby when I heard sirens.	X											
45	I felt I wasn't alone after reading other people's stories.	X											
46	I wanted the children to leave me alone.	X											
47	I had to look after my other children.	X											
48	I became very close to my spouse.	X	X										
49	I was relieved to know that my spouse was still grieving and still cared about the baby.	X											
50	I was pregnant again.	X	X	X	X								
51	I felt the best thing for me was to have a baby.	X	X										
52	I tried to have another child.	X											
53	You know in your mind that you are still a mother but physically there is no baby.	X	X										
54	We adopted a baby.	X											
55	We moved.	X	X										
56	We cleaned everything in the house before the next baby arrived.	X											
57	I accepted the situation.	X											
58	I had the next baby sleep in our room.	X											
59	I know that the baby's death is not anything that people have done.	X	X	X									
60	I blame God.	X											
61	I became indifferent to God.	X											
62	I asked God's help.	X	X										
63	I know the baby is in heaven.	X											
64	I had to go on.	X	X	X									
65	I could see babies and not turn away.	X											
66	I distanced myself from babies.	X											
67	I shared the baby pictures with friends.	X	X	X	X								
68	I sent everybody copies of the funeral.	X											
69	I read the sympathy cards.	X											

Table 9 (continued)

	Statements	1	2	3	4	5	6	7	8	9	10	11	12
70	I kept a journal.	X	X										
71	I kept a lot of the baby's clothes.	X	X										
72	I looked through the baby's things.	X	X										
73	I shut the door and left the baby's room as it was.	X	X										
74	I try to remember as much as I can.	X	X										
75	I sat in the baby's room.	X											
76	I questioned whether there was something wrong with me when I laughed.	X	X										
77	I check my children and my husband when sleeping.	X											
78	I find it easier acknowledging that the baby lived.	X											
79	I went to national SIDS conferences.	X											
80	I did in-services for Victims Services.	X											

frequency

[X] = statement deemed to contain similar content

to terms with the baby's death and at the same time maintaining connection with their partner. Emotional support and information may result from talking with others who have suffered a similar loss.

Attending the funeral was reported by 5 mothers. Information gathering was important: 6 mothers gained information from reading while 3 mothers went to the doctor for advice and information. Returning to work (4) and coping by keeping busy (4) suggest that mothers found it helpful to be occupied with various activities. Four mothers had another child as demonstrated by their reporting being pregnant again and 2 mothers stating that the "best thing for me was to have another baby."

Sharing baby pictures with friends helped 4 mothers. Some mothers (4) reported being overwhelmed with grief. Two mothers reported feelings of guilt, while another two believed that the baby's death was unpreventable. Mothers cried (4) and some reported feeling angry (2). Professional help was used by mothers: the doctor (3), counselling (3), use of medications (2), and hospitalization (1).

Fathers

Five out of the eleven fathers reported getting support from the local chapter of CFSID and 3 fathers used the SIDS help line. Only limited active involvement in the support group was reported by fathers: organizing the telephone help line (1), leading support group meetings (1). Talking was reported relatively frequent; talking to their spouse (4), talking to other people (3), talking to a relative (3), talking to someone who had lost a baby (1). Fathers reported crying (3), being angry (3), looking after children (3), having another baby (3), and trying to make sense of the baby's death equally

Table 10

Frequency of use of fathers' statements.

	Statements	frequency										
		1	2	3	4	5	6	7	8	9	10	11
1	I talked to friends at work.	X	X									
2	I did a lot of talking about it.	X	X									
3	I talked to people.	X	X	[X]								
4	I talked to a relative.	X	X	X								
5	I talked to others who understand because they have lost a baby.	X										
6	I talked to my spouse.	X	X	X	X							
7	I did not talk that much to my spouse.	X										
8	I don't talk about it a lot.	X										
9	I drank more after the baby died.	X										
10	I exercised or did physical work.	X	X									
11	I did a lot of day dreaming and thinking.	X										
12	I worked to keep my mind from thinking about it.	X	X									
13	I spent a great deal of time playing the piano.	X										
14	I didn't work any more.	X										
15	I prayed a lot.	X										
16	We called family and friends.	X	X									
17	I had support of family and friends.	X										
18	We went away with my spouses' relatives.	X										
19	I lost track of time.	X										
20	I visited the grave.	X	X									
21	We kept the baby's door closed.	X										
22	We had a funeral.	X										
23	I didn't go to the cremation.	X										
24	When I saw the baby laid out, I knew my child was not in that body.	X	X									
25	I was glad when I knew the body was gone.	X										
26	I am happy having the baby's cremated remains in a warm house full of love.	X										
27	I cried and cried for a long time.	X	X	X								
28	I almost had a break down.	X										
29	I really felt depressed.	X	X									
30	I felt overwhelming emptiness.	X	X									
31	I was devastated.	X										
32	I had a hard time.	X	X									
33	Sometimes I really hurt.	X	X	[X]								

Table 10 (continued)

	Statements	frequency										
		1	2	3	4	5	6	7	8	9	10	11
34	I was angry.	X	X	X								
35	I felt a sense of heaviness.	X										
36	I fought with my spouse.	X										
37	I gave my spouse a hug.	X										
38	I helped my spouse get over it.	X										
39	I became closer to my spouse.	X										
40	I felt helpless to help my spouse.	X										
41	I had to look after the older children	X	X	X								
42	I always acknowledge the baby as part of the family.	X	X									
43	We had a new baby.	X	X	X								
44	I found it hard with the next baby.	X										
45	I was afraid that the same thing would happen to our next baby.	X										
46	I said to hell with religion.	X										
47	I said "God you've always said that you'll be there for us".	X										
48	We began to go to church.	X										
49	I like to think that I do everything in the baby's name.	X										
50	I thought I wouldn't be lucky enough to have children after the baby died.	X										
51	I thought God never figured I was a good enough parent so he took my baby away from me.	X										
52	We asked "Why did a little baby go?"	X	X	X								
53	I'll meet my baby in heaven.	X										
54	I'll know and understand everything when I get to heaven.	X										
55	I think that life must go on.	X	X	X	X							
56	I believe that there is nothing that we could have done.	X										
57	I think my baby has been spared.	X	X									
58	I have a little angel on shoulder that protects me on bad days.	X										
59	I organized the 24 hour SIDS line.	X										
60	I run as many parent support groups as I can make.	X										
61	I turned first to the minister.	X										
62	I found the SIDS group very helpful.	X	X	X	X	X						
63	I phoned the SIDS help line.	X	X	X								
64	Knowing that others have lived through the experience makes you see that you can live.	X										

Table 10 (continued)

	Statements	frequency										
		1	2	3	4	5	6	7	8	9	10	11
65	I needed to understand.	X										
66	I asked questions at the SIDS meetings.	X										
67	I found the emergency response team very sympathetic, helpful and protective.	X										
68	I watched films about SIDS.	X										
69	I was scared to death to see my friend's baby.	X										
70	I checked the next baby three to four times during the night.	X	X									
71	The first thing I do when I come home or wake up is check the children.	X										
72	I would wake up at night and check that my wife was breathing.	X										
73	I knew the baby was gone.	X										
74	I couldn't understand, the world wasn't stopping, mine had.	X										
75	I had bad dreams.	X										
76	I remember the baby's birthday and Christmas.	X										
77	I decided that the quality of life was more important than work.	X	X									
78	I remember the last night I spent with my baby.	X										

[X] = statement deemed to contain similar content

frequently (3). Some fathers believe life goes on (4) or reported having different priorities (2). Fathers had fear and anxiety: anxiety about the safety of the next baby (2) and fear for the other children or spouse (1).

Concept Map Comparison

Mothers' Concept Map

The mothers' concept map (Figure 5) has been divided into 4 regions that each make logical sense: "Grief", "Transitions", "Moving into the Future", and "Remembering". The themes of "Coming to Terms with the Baby's Death" (#3), "Being Sad, Angry and Grieving" (#10), and "Getting Comfort Through Being Alone" (#9) all express stages in the grief process. The grief process starts with cluster #3, the need to attend to practical issues of death, moves into the period of joyless emotions mothers experienced (cluster #10), and onto time to be alone to deal with the pain of the baby's death (cluster #9).

The region of the map "Transitions" is part of the grief process but seems to reflect that, within that process, mothers needed to make both physical and psychological changes to move forward. Mothers needed to come to terms with the physical absence of the baby and how they perceived themselves. Psychologically, previously held beliefs were shaken and mothers required time to make a new sense of the uncertainty of life. The upper portion of the mothers' concept map shows a progression through grief, moving from the right hand side of the map to the left.

At the centre of the mothers' concept map is the region named "Remembering" made up of one cluster (#8) "Remembering the Baby".

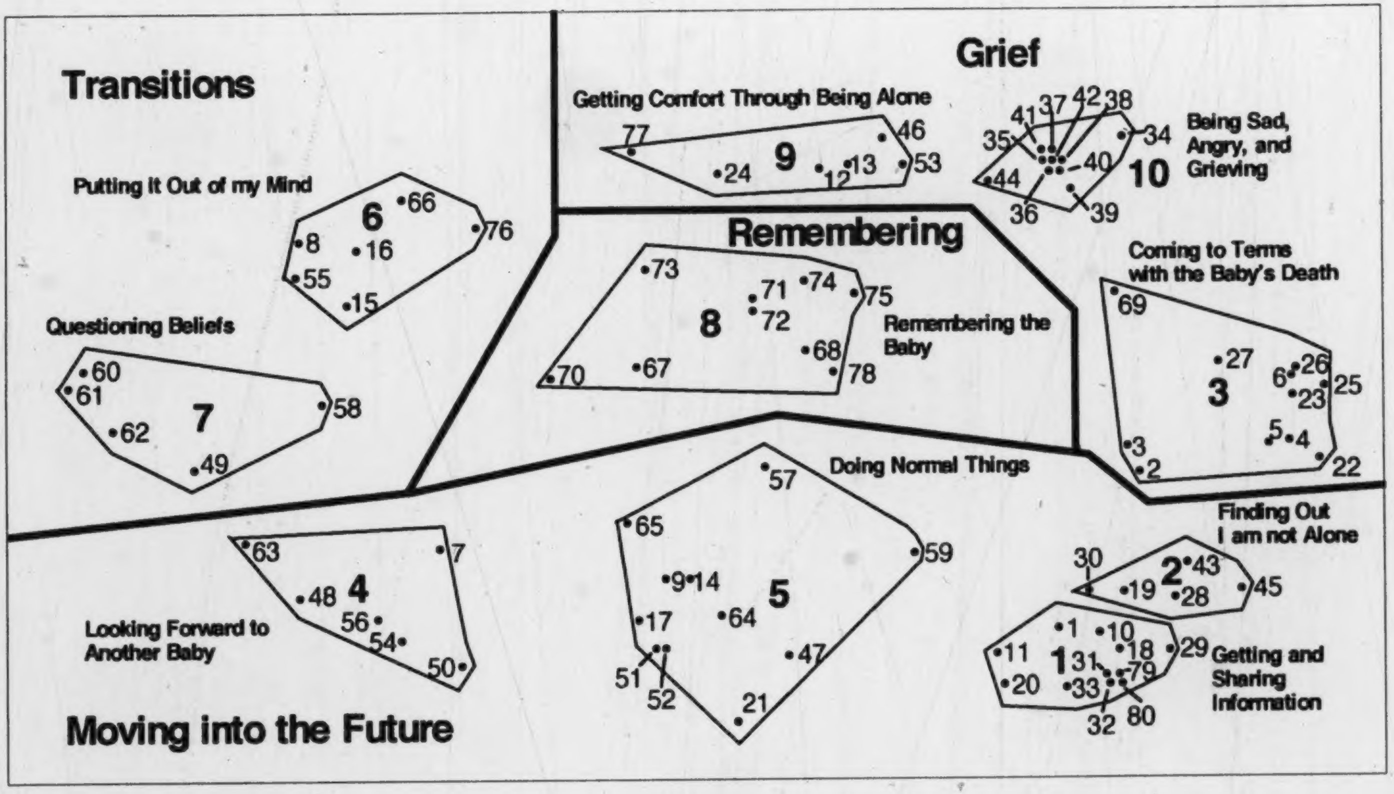
Transitions
Grief
Remembering
Moving into the Future
Getting Comfort Through Being Alone
Being Sad, Angry, and Grieving
Putting It Out of my Mind
Remembering the Baby
Coming to Terms with the Baby's Death
Questioning Beliefs
Doing Normal Things
Finding Out I am not Alone
Looking Forward to Another Baby
Getting and Sharing Information
1
2
3
4
5
6
7
8
9
10
77 24 12 13 46 53
41 37 42 38 35 34 40 44 36 39
66 8 16 76 55 15
73 71 74 75 72 68 70 67 78
69 27 26 6 23 25 3 5 4 2 22
60 61 62 58 49
57 65 59 9 14 17 64 47 51 52 21
30 43 19 28 45
1 10 11 18 29 31 79 20 33 32 80
63 7 48 56 54 50

Figure 5
Mothers' 10 cluster concept map, categorized into major themes.

This suggests that throughout the mothers' grief process and their adjustment back to normal living, memories of the dead baby are central to both processes ("Grief" and "Moving into the Future"). For mothers, living their life may always reflect the two, almost parallel, processes that this map displays; normal life activities accompanied by some level of grief for the dead baby.

The lower portion of the mothers' concept map also presents a past toward the future progression for the region "Moving into the Future". Moving from the left hand side of the map to the right indicates a movement from internal ways of coping to more external types of activities and behaviors. In this region, mothers start the process of moving back to normal living and on into the future by becoming informed and realising that others who have suffered a similar tragedy have gone on living (clusters 1 and 2). Mothers reported that they did normal things such as going back to work and looking after their children (cluster 5). Normal life and looking to the future for mothers means having children. Having another child in the family is an orientation away from the past and into the future (cluster 4).

Fathers' Concept Map

The fathers' concept map (Figure 6) has been divided into 3 regions: "Grief", "Acceptance", and "Transitions." Starting with cluster #7, "Being Sad and Depressed", the progression through clusters "Trying Not to Think About It" (#3), "Seeking Comfort and Understanding" (#4), "Talking" (#2) reflects the grieving process. The most meaningful way of looking at the fathers' concept map is to examine it in a counter clockwise direction. Denial is suggested by cluster #3. Moving from the bottom right hand corner of the map, forward progress through grief is evident and continues into the region "Acceptance".

Fathers come to terms with their life without the baby by finding ways to put an end to the tragedy and moving on with life (#10), acknowledging the baby's life and death (cluster #8), and by having memories of the baby (#9). In a central position at the bottom of the fathers map is a region named "Transitions". This region is made up of one cluster (#6) that indicates that for a period of time fathers suffer greatly from their baby's death. The baby's death makes life very uncertain and this causes fathers considerable anxiety.

The single cluster (#5), "Distancing", at the centre of the map, suggests that fathers do not want to be in contact with aspects of the painful situation arising from their baby's death. Fathers may again be using denial to cope with the baby's death and as a result try to focus on the present, such as looking after the other children and having a new baby; both of these are part of normal living.

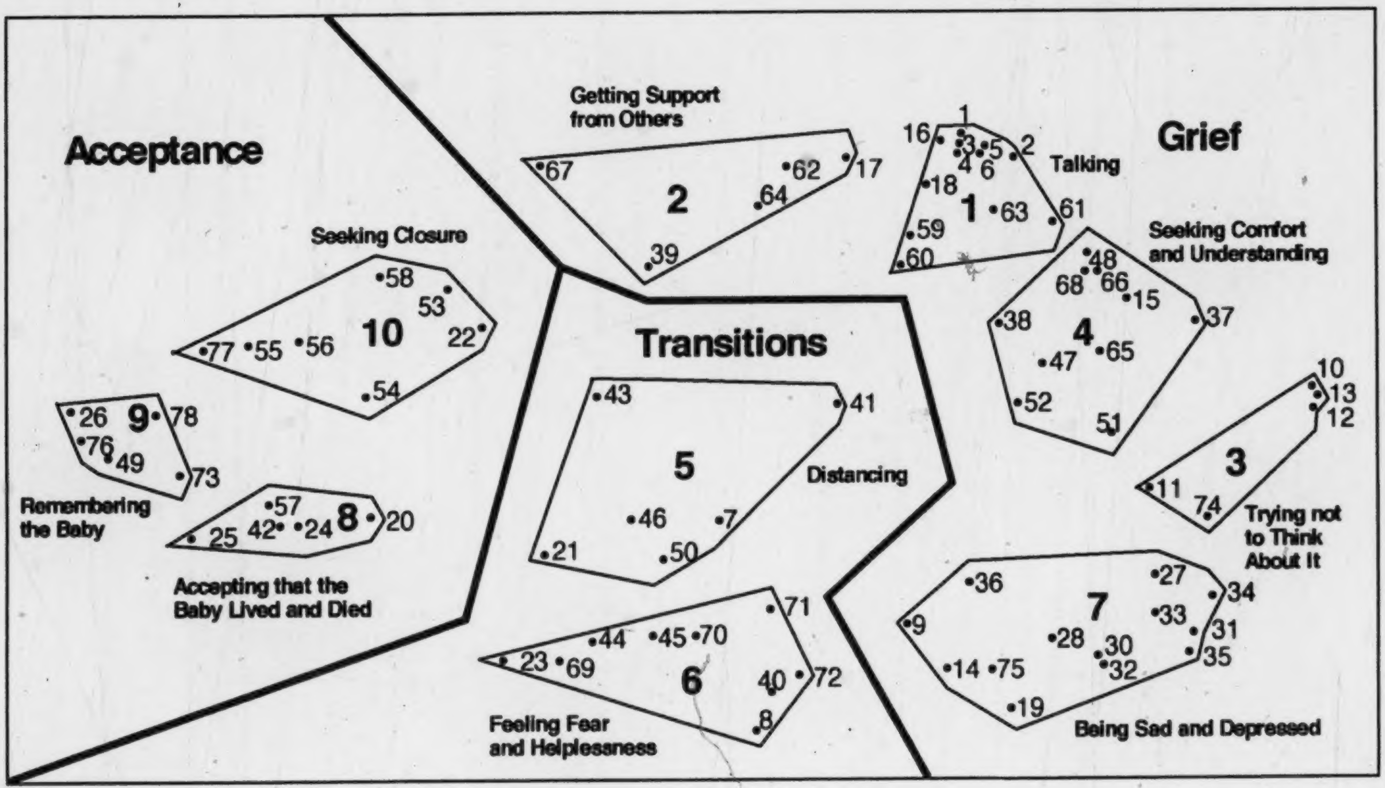
Acceptance
Grief
Transitions
Getting Support from Others
Talking
Seeking Comfort and Understanding
Seeking Closure
Trying not to Think About It
Remembering the Baby
Accepting that the Baby Lived and Died
Distancing
Feeling Fear and Helplessness
Being Sad and Depressed
1
2
3
4
5
6
7
8
9
10
67 62 17 64 39
16 1 3 5 2 4 6 18 63 61 59 60
48 68 66 15 38 37 47 65 52 51
10 13 12 11 74
58 53 22 77 55 56 54
26 78 76 49 73
57 25 42 24 20
43 41 46 7 21 50
71 44 45 70 23 69 40 72 8
36 27 34 9 33 31 28 30 35 32 14 75 19

Figure 6
Fathers' 10 cluster concept map, categorized into major themes.

CHAPTER 5: DISCUSSION AND CONCLUSION

The purpose of this research was to extend the understanding of mothers' and fathers' experience of the death of a baby from sudden infant death syndrome. The first objective of the study was to identify ways in which mothers and fathers responded to their baby's death. Two separate lists of statements were compiled; one for mothers and the other for fathers.

The second objective was to investigate these two lists of statements separately using concept mapping to identify underlying themes of responding used by mothers and fathers. In each of the two resulting concept maps, ten themes were identified that described mothers' and fathers' responses to the death of their baby. The themes identified for mothers were:

"Getting and Sharing Information",
"Finding Out I'm Not Alone",
"Coming to Terms with the Baby's Death",
"Looking Forward to Another Baby",
"Doing Normal Things",
"Putting it Out of My Mind",
"Questioning Beliefs",
"Remembering the Baby",
"Getting Comfort Through Being Alone",
"Being Sad, Angry and Grieving".

The ten themes for fathers were:

"Talking",
"Getting Support from Others",
"Trying Not to Think About It",

"Seeking Comfort and Understanding",
"Distancing",
"Feeling Fear and Helplessness",
"Being Sad and Depressed",
"Accepting that the Baby Lived and Died",
"Remembering Baby",
"Seeking Closure".

Finally, the third objective was to identify gender differences in the way in which mothers and fathers respond to the death of the baby from SIDS. These differences were investigated in three ways: the two master lists of statements were examined for statement similarities, the frequency of use of statements was compared, and the mothers' and fathers' concept maps were further divided into regions and examined for similarities and differences. Of the statements on the mothers' and fathers' master lists which were not identical, seventy percent of the statements shared similar content.

Independently, mothers and fathers reported that their main method of coping had been involvement with the local chapter of CFSID. In addition mothers frequently reported getting support from family and friends, returning to work, talking to their spouse, gathering and sharing information, remembering the baby, and having another child. The latter, was for some, a form of coping and for others a stage in healing. Although fathers reported a similar range of statements to mothers, they appeared not to use the list with the same frequency as mothers. Fathers talked to their spouse, cried, were angry, looked after other children, had another baby, tried to make sense of the baby's death and reported the belief that life goes on.

Examination of the regional themes of the mothers' concept map revealed that mothers grieve ("Grief"), make changes to their lives ("Transitions"), move on with their lives ("Moving into the Future"), and remember the baby ("Remembering"). The concept map for fathers indicates that fathers grieve ("Grief"), come to accept the situation ("Acceptance"), and make life changes ("Transitions").

Discussion

Previous research investigating parental coping and grieving after a baby dies from SIDS has provided considerable information about mothers but no definitive description of fathers' coping. Much of our knowledge of parents' experiences with SIDS has come from research that reported anecdotal statements by parents or was constrained by predetermined questions. The result is information without form or a frame work. The method of concept mapping used in this study has resulted in the conceptualization of the experience by mothers and fathers following the death of the baby from SIDS.

Mothers and fathers each generated a master lists of statements (80 and 78 items respectively); these lists indicate that both genders responded in a variety of ways to death of their baby. No comprehensive list of coping statements appears in the literature although Carroll and Shaefer (1993-94) refer to the SIDS Parent Coping Inventory having 93 items that identify behaviors parents use to cope with grief and on-going family life. Seventy percent of the statements reported by mothers and fathers in this study were deemed to be the same: talking, getting support from others, being involved with a support group, being sad and depressed, attending the funeral, becoming informed about SIDS, having another baby, questioning beliefs, and keeping busy.

Some gender biases are evident in some of the statements that were not similar for mothers and fathers. For mothers, differences reflect the female role of being a mother: seeing their dead baby, questioning their motherhood, and doing normal things with other children . The traditional protector role for men as husbands and fathers may be reflected by fathers' statements of either helping or feeling helpless to help their spouse with the baby's death. As a result of the sudden, unexplainable death of an apparently healthy baby, fathers report behaviors of checking on family members to reduce feelings of anxiety. In some cases the difference between mothers and fathers is individual: a father's belief that an angel protects him on bad days, a mother's need to know that her spouse still cares about the dead baby.

Further understanding of how mothers and fathers respond to the death of a baby from SIDS comes from the concept maps. Interpretation of the concept maps can provide a description of the implicit theory of the experience being investigated (Trochim, 1989b) and be used "as a basis for developing theory" (Trochim, 1989b, p. 88). In this chapter the concept maps are discussed based on Trochim's assertion that concept mapping may be used as a basis for developing theory or as tool for shedding light on processes. The numbers of participants reporting using statements in each of the ten clusters in both concept maps indicates that the themes described are not those of isolated individuals but shared by other participants. This, therefore, serves as a basis for theorizing about the experience of mothers and fathers whose baby died from SIDS.

Mothers' Experience

Although the ten solution concept map for mothers describes many of the issues already addressed in the literature, this research provides a frame work for better understanding the mothers' experience. Using the concept mapping method, it appears that there are four major themes that reflect the recovery process experienced by mothers whose baby died from SIDS: "Grief", "Moving into the Future", "Transitions", and "Remembering". Two of the processes, "Grief" and "Moving into the Future" are more or less parallel to one another suggesting that they co-exist. Grieving ("Grief") is a journey that takes time and moves a person from one place to another: this movement may be suggested in the mothers' concept map. Moving forward with life is also a journey which progresses with the grieving process and then continues on. The theme of "Transitions" represents a time of making changes, as the mother moves through the grieving process. The "Transition" stage might arguably be part of the grieving process but has been identified in this study as a different phase in the healing process. The literature offers no information about how mothers move from a state of grief to normal living.

The fourth major theme, "Remembering" is made up of one cluster (#8). The location of this cluster and the fact that a single cluster forms a major theme, suggests that it is static or fixed. Memories are important and part of grieving (Worden, 1991). However, the centrality of remembering may mean that memories of the baby are present and important to the mother for the rest of her life. In this study some babies died 12 - 16 years ago, but are still remembered as seen by mothers' participation in this study. DeFrain, Ernst, Jakub, and Taylor (1991) recorded many parental anecdotes about the importance of memories. In this study, for mothers, remembering the baby takes the form of baby photographs and mementos.

Grieving is a process and this is shown by the major theme "Grief". "Grief" is composed of three clusters: "Coming to Terms with the Baby's Death", "Being Sad, Angry, and Grieving", and "Getting Comfort Through Being Alone". The relationship of one cluster to another may represent the grieving process from the time of the baby's death, through the pain and sorrow, to a period of trying to deal with the suffering.

When a healthy baby dies for no reason a mother is in a state of shock and disbelief. Mothers struggle to understand that their apparently healthy baby is dead. Babies should not die; they are just starting out on life. The theme "Coming to Terms with the Baby's Death" reflects how mothers come to accept that death is a reality. In seeing the dead baby, some mothers express the feeling that the body is so different, they know that the baby has gone. Planning and having a funeral is a time honoured ritual that marks the end of a life, and this again brings mothers the reality that the baby is dead. Being present at situations that confirm the dead person will not be returning, helps mothers acknowledge the baby is dead. For some parents, seeing the dead baby in the casket may help to remove memories of their finding the baby dead at home (DeFrain, Taylor, & Ernst, 1987).

Difficult as it is to accept the baby's death, so is the sadness and pain that follows. Mandell, McAnulty, and Reece (1980) described mothers coping as being withdrawn and depressed while DeFrain (1991) reported that they cry and want to talk about their experiences. During the early period following the baby's death, Ostfeld, Ryan, Hyatt, and Hegyi, (1993) found that sadness/depression, concentration difficulties, restlessness, sleep disturbances and anger were the five most pronounced symptoms of grieving for mothers. Some of these symptoms are evident in the theme "Being Sad, Angry, and Grieving". Mothers were depressed and expressed the sense of being overwhelmed by all the feelings that the baby's death brought. Crying was reported. Mothers did express anger; anger at not being a mother.

The pain may be so intense that escape from it came by dissociation; blocking out major periods of time. Pain is very personal and elusive of oral/verbal description. Perhaps the best way to deal with the pain is by being alone, as described by the theme "Getting Comfort Through Being Alone". DeFrain, Taylor, and Ernst, (1987) write that "it is not possible to share pain". "Getting Comfort Through Being Alone" may take various forms from physically being alone, to escaping pain by taking medication, to struggling within yourself about whether you are still a mother now that the baby is dead. Some mothers required help from health professionals.

A view of guilt being pervasive and common among SIDS parents is present in the literature (Ostfeld, Ryan, Hyatt,& Hegyi, 1993; DeFrain, Taylor, & Ernst, 1987; Dryegov & Matthiesen, 1987) and even described as being "inescapable" (DeFrain, Ernst, Jakub, & Taylor, 1991). No theme of guilt was found for this group of mothers. One item on the mothers' master list of statements referred to having 'a lot of guilt'; only two mothers in this study reported feeling guilty. This statement was placed with other statements in the "Being Sad, Angry, and Grieving" theme. An explanation for the lack of guilt reported by the mothers in this study may result from the recent, fairly broad based, definition of SIDS, and increased awareness of SIDS from national "Back to Sleep" campaigns. Guilt likely stems from within the individual attempting to make sense of the baby's death. It is possible that as gathering and sharing information about the nature of SIDS was important to women in this group, this reduced feelings of guilt.

The themes "Coming to Terms with the Baby's Death", "Being Sad, Angry, and Grieving", and "Getting Comfort from Being Alone" indicate the components and process of mothers' grieving. These themes suggest the movement through the grieving process from the time of death. Time was not a variable in the study but this grief stage likely occurs in the early period after the baby's death.

According to Ostfeld, Ryan, Hyatt, and Hegyi, (1993) six months after the baby's death there was a reduction in the intensity of mothers' grief. Perhaps it is at this time that mothers actively start making changes to their way of thinking about life and living. This may be reflected in the major theme "Transitions" by the theme "Putting it Out of my Mind" that involves behaviors that help mothers deal with their loss, and the theme "Questioning Beliefs" when mothers struggle with ways with which to cope with, a now, uncertain world.

Changes in the mothers' behavior helps them make the transition from grieving to more normal living. Being busy was a common way for mothers to distance themselves from their pain and loss; being actively occupied keeps them from thinking about the baby. Putting physical distance between themselves and the place associated with the baby is reported in the literature; in two studies of maternal coping with SIDS, approximately half the families in each study moved their residence within 6 months of the baby's death (Ostfeld, Ryan, Hyatt & Hegyi, 1993; Price, Carter, Shelton & Bendell, 1985). However, moving house was only used by 2 of the participants in this study. In the study of Price et al., one-quarter of the mothers had an "unsatisfactory adjustment" six months after the baby's death. There is no explanation as to what is meant by adjustment but this may refer to the transitional period identified by concept mapping.

The birth of a healthy baby creates dreams, expectations and hopes for the future. The unexpected death of a healthy baby robs parents of this investment in a future and the rules of life have been changed by one so young and apparently healthy dying. Mothers respond to this new uncertainty with anxiety and reassessing their beliefs about God. As found by DeFrain, Ernst, Jakub, and Taylor (1991), mothers differ in their quest to make existential sense of their life: some lose faith, some blame God, and some lean heavily on God for comfort.

The two themes of "Putting it Out of my Mind" and "Questioning Beliefs" represent the behavioral and psychological changes mothers need to make to move through their grief and on to the future. There is no information about the transitional phase that mothers pass through from their grief to the time when they regain their former level of 'personal happiness' (DeFrain, 1991, p.225). These two themes may represent that transitional stage that allows mothers to move back to normal living.

While mothers move through a grieving process, it is likely that they concurrently strive towards living normally: "Moving into the Future".

Becoming informed about SIDS and sharing that information may be the start of this process as represented in the themes of "Getting and Sharing Information" and "Finding Out I'm Not Alone". In their search for information, mothers go out and meet other people; they are existing in a world outside their immediate home. For mothers in this study, the main source of support came from their participation and involvement in a CFSID support group. Interactions with other parents whose baby had died provided evidence that it is possible to come to terms with the death and 'go on living'. In addition to providing practical support, parent support groups may be safe places for some parents to grieve and remember the baby. Mothers, on average, attend more SIDS support group meetings than fathers (DeFrain, Ernst, Jakub, & Taylor, 1991); the same situation was found in this study.

Part of the process of moving on with life involves the theme of "Doing Normal Things". For mothers, normal life is about going to work, having children, and looking after children. Having children and looking after children fits society's expectations of the traditional mother. In this study 3 of these mothers reported that they returned to work. Working outside the home is described in the literature as a coping strategy for men (DeFrain, 1991), not for women. For many mothers investing in the future is represented by mothers having another child. For some mothers in this study this meant a pregnancy, but for one mother it meant adopting a baby. In Carroll and Shaefer's study (1993-94), 50% of mothers reported coping by having another baby or adopting a baby. While having another child helps the mother to move forward into the future, it also helps reduce the feelings of grief for the dead baby (Ostfeld, Ryan, Hiatt, & Hegyi, 1993). Another child allows mothers to invest energy and love in someone else. Taking care of a baby is externally-directed behavior that reduces the time a mother may spend thinking about the dead baby; a new baby is an adaptive way of dealing with the loss that results in reduction of depression and assists adjustment (Videka-Sherman, 1982).

Fathers' Experience

Less is known about how fathers react after the death of an infant from SIDS. Much of that information comes from anecdotal reports. Some aspects of fathers' responses found in this study have been reported in the literature. The use of concept mapping in this study has also provided a frame work for fathers' experience of SIDS and as a result has identified three major themes that reflect the fathers' recovery process: "Grief", "Acceptance", and "Transitions". Unlike the mothers process for recovery, fathers do not have a process that runs parallel to that of "Grief". Instead the concept map for fathers suggests a progression through the three major themes in the order "Grief", "Acceptance", and "Transitions".

The theme of "Transitions" coincides with the last portion of the grieving process for fathers; the major theme of "Transitions" is in the same vertical plane as cluster #2 "Getting Support from Others". This suggests that as fathers are able to reach out for support, they are making changes at both a psychological and behavioral level. As fathers move out of the more acute time of grief, they move into a stage of "Acceptance".

For fathers, the major theme of "Grief" is made up of five clusters: "Being Sad, and Depressed", "Trying Not to Think About It", "Seeking

Comfort and Understanding", "Talking", and "Getting Support from Others". As these five cluster were endorsed by 45% - 63% of the fathers, they represent fathers' grieving process.

There is no doubt that fathers grieve and their sense of loss is painful. The theme "Being Sad and Depressed" indicates that fathers do suffer when their baby dies from SIDS. DeFrain (1991) and Mandell, McAnulty, and Reece (1980) reported that men are less emotional and less able to cry than women. In another study using checklists for data collection, Feeley and Gotlieb (1988-89) found that mothers cried and thought about the baby more than fathers. Three fathers (25%) reported dealing with the loss of the baby by crying but this study has no quantitative measure of crying to know how this differs from mothers' crying. Society does not expect men to cry but rather to be strong for the family. However this does not mean that fathers do not suffer . Fathers reported feeling hurt, devastated, depressed and overwhelmed by emptiness.

Anger is part of the theme of "Being Sad and Depressed": three fathers reported being angry at themselves for not protecting the baby, angry when work prevented them attending support meetings, and fighting with their spouse. Again, anger has not been quantified in this study but both parents reported feelings of anger. Anger has been reported as being greater for parents whose baby is a SIDS death than for other neonatal deaths. Mandell, McAnulty, and Reece (1980) found that bereaved fathers were more angry and aggressive than their wives. Male anger may be part of the self-blame processes described: Defrain, (1991), Mandell, McAnulty, and Reece (1980).

Fathers may acknowledge or accept that the baby has died but they have a very difficult time facing what that really means. The theme of "Trying not to Think About It" indicates that 5 of the 11 fathers reported that they kept themselves busy and even increased their involvement in some of these activities. The hoped for end result was not to think about the dead baby. Consistent with Mandell, McAnulty, and Reece's (1980) observations, it appears that some fathers cope by denying the baby's death to escape from dealing with the pain. In this study, it may be that denial was used for a period of time before fathers sought comfort and ways to deal with their loss. This period of denial may provide fathers some temporary relief from their pain before continuing with the difficult work of grieving and adjustment.

Fathers attempted to find relief from their pain in various ways as represented by the statements in the theme "Seeking Comfort and Understanding". Fathers, like mothers, want to understand the nature of SIDS. They are less active in searching for information, but understanding brings some comfort as in the statement "I asked questions at the SIDS meetings" in cluster #4. Comfort was achieved for some fathers by taking on a protective or managerial role (Mandell, McAnulty, & Reece, 1980) as in helping their spouse to cope with her grief. Continuing or reestablishing contact with God may bring consolation or help to make sense of the baby's death. According to Thearle, Vance, Najman, Embleton, and Foster (1995), those that benefit most from religious affiliation are those that attended church regularly prior to the baby's death; depression is reduced in this group. Some fathers, just as do their spouses, struggle with previously held beliefs about God that now, no longer seem to make sense. Fathers strive to make sense of "Why this happened?". Trying to make sense of this question is necessary for fathers to move forward through their grief process.

As fathers gain some sense of comfort and understanding of the situation, they are able to talk about the baby's death. Fathers do talk as indicated by cluster #1, "Talking"; they talk mainly to their spouse, but also to various family members and to people outside the family unit. Emotional support is gained from talking to other parents who have experienced the death of a child. Mothers reported that fathers were much less able to talk than themselves (DeFrain, 1991) but this may reflect that the time that has elapsed since the baby's death was not long enough for fathers to have reached the point in their grief were they were comfortable talking. In the initial stages of their grief, the painful feelings plus denial may prevent fathers from talking. Once fathers are able to share their feelings and experience by talking, they are able to reach out to others for support ("Getting Support from Others") and extend their world of grief.

When fathers have gained more support from outside their immediate family, they appear to come to terms with the baby's death and seek closure. This is indicated by the major theme, "Acceptance" made up of three clusters, "Accepting that the Baby Lived and Died", "Remembering the Baby", and "Seeking Closure". Accepting the reality of the baby's death is important so that fathers may move on with their lives. The reality of the baby being dead comes from seeing the baby's body, visiting the grave and struggling with how to answer the question "How many children do you have?". The answer to the latter question varies as one participant said according to how you feel. The very question makes fathers face the fact that the baby is dead. For some, reality is changed to bring more comforting thoughts about the death: "I think my baby has been spared".

In accepting the reality of the baby's death, fathers try to bring this period of suffering to an end by "Seeking Closure". Some closure or reality of the death comes early on when the family organizes and participates in a funeral. However, as part of this process fathers attempt to bring themselves comfort by the belief that they will meet their child in heaven and that the death was unpreventable. Finally, believing that "life goes on", moves fathers forward. However, for some, the baby's death may result in leading life with different priorities.

Fathers also remember the baby (Carroll & Shaefer, 1993-94; DeFrain, 1991; DeFrain, Ernst, Jakub & Taylor, 1991) particularly on special anniversaries: this is represented by the major theme, "Remembering". Remembering the baby is not central to the fathers' healing process as it is for the mothers.

Believing life must go on is one thing, but actually getting on with living requires fathers to make some changes as suggested in the major theme "Transitions". Two clusters comprise the major theme of "Transitions". Changes fathers made involved thoughts and actions that placed some distance between themselves and the dead baby ("Distancing"): talking less about the dead baby with their spouse, changing their attitude to religion. Doing normal things such as looking after other children also helped distance fathers from the baby's death. Having another baby brought even more distance and returned them into living in a different present.

A new baby is not easy for some fathers who are beset with fears and anxiety resulting from a baby's death. Expectations of how the world operates have been shattered with the death of their baby, and as a result fathers suffer from feelings of anxiety and not being in control ("Feeling Fear and Helplessness"). The fears and concerns of fathers for the well being of other children or the next baby are documented by (DeFrain 1991). The safety of their spouse caused additional anxiety for a father in this study. The unexpected death of their baby plunged fathers not only into feelings of pain but into an insecure world; situations that previously were non-anxiety provoking, caused fathers much distress. Being able to live and overcome this anxiety is part of the transition phase. No theme emerged in this study equivalent to the major theme of "Moving into the Future" found in the concept map for mothers.

Conclusions

The results of this research indicate that mothers and fathers whose baby died from SIDS both respond to this loss in a variety of ways. Some of the parents' responses reflect aspects of the grieving process while others reflect ways of coping. Seventy percent of the statements on the master lists were deemed to be the same for mothers and fathers. The remaining 30% of the statements that were not similar, reflect gender and individual differences.

Mothers' experiences are described by ten themes on the mothers' concept map. The major themes represented in the mothers' concept map indicate that mothers grieve ("Grief'), get on with their lives ("Moving into the Future"), remember the baby ("Remembering"), and make changes ("Transitions"). The themes "Grief" and "Moving into the Future" suggest that these two processes proceed simultaneously and help move the mothers from focussing on internal activities to external behaviors. Mothers make psychological and behavioral changes ("Transitions") that help them move through their grief. Remembering the baby is both part of mothers' grieving and moving on with life after the baby's death.

Fathers' experiences are described by ten themes in the fathers' concept map. The major themes in the fathers' concept map indicate that fathers grieve ("Grief"), accept the baby's death ("Acceptance"), and make changes to move on with life ("Transitions"). Although there was not a major theme of remembering, fathers do remember their baby as represented by statements in cluster #9.

Mothers are very active in their search for understanding the nature of SIDS and their baby's death. Remembering the baby is central to both mothers' grieving and returning to normal activities. Having another baby appears to be part of some mothers' lives after the death of an infant. Mothers sought medical and professional help to deal with their baby's death.

Fathers may dull the initial pain or reality of the baby's death by denial. Fathers reported talking as a way of helping them deal with their baby's death. Those fathers that were interviewed spoke freely and without prodding from the researcher. Anxiety and fear are emotions experienced by fathers after the death of their baby from SIDS.

Both fathers and mothers suffer sadness and pain after their baby dies, as shown by clusters #7 and #10 on the fathers' and mothers' respective concept maps.

Although two mothers reported some feelings of guilt, guilt was not found as a theme or major themes in this study.

Limitations of the Study

Certain limitations must be kept in mind when interpreting the results of this study. The information in this study is based on self-report; in view of the nature of the experience being researched and the range in time since the death of the baby, painful memories may be under reported or be inaccurately remembered.

No account has been taken for the amount of time that has elapsed since time of death, the sex of the baby that died, whether there were other children in the family, or whether parents were married or single at the time of the baby's death.

No demographic information was gathered as to the ethnicity of this group of participants, and this may affect generalizability.

Practical Implications

The findings from this study confirm that parents whose baby dies from SIDS suffer the loss with much pain and the manifestation of depressive and anxious symptoms. The results suggest that fathers' denial of the baby's death is not necessarily a maladaptive way of coping. Denial may help the fathers cope during the most painful period of their grief. Fathers do talk but this may be after some of the initial pain has reduced. Mothers need for support from family, friends or health professionals helps the mothers deal their pain of loss, and this should not be perceived as maladaptive in their grieving process.

While fathers are less likely to seek professional help or support groups, this may reflect that they are not ready for such help or interventions in the grieving period immediately following the baby's death. Help offered at a later time may be more readily acceptable. Fathers suffer from anxiety which may need to be the focus of counselling.

Knowledge of differences in the processes of healing for mothers and fathers has important implications both for individual or couple counselling, in helping partners understand how their spouse may be dealing with the baby's death.

Having another baby may be a positive way of coping for some mothers as becoming actively involved in the care of the child appears to reduce symptoms of depression and provides meaning. Another child is not seen as a replacement baby. Mothers try to go on with normal living while grieving at the same time. It appears that remembering the dead baby may be life long.

Future Research

Additional studies are required to validate these reported findings and to explore their reliability in other groups of parents whose baby died from SIDS. Studies using participants from different ethnic groups, especially those where the risk of sudden infant death is high, are needed to determine whether the recovery experience is the same or different for all mothers and fathers.

More information is needed about how the presence or absence of children in the family affect parents' coping; research into the recovery process for parents with and without children would be necessary to clarify this issue.

A survey of a larger number of SIDS parents is needed to compare gender coping based on the lists of statements generated in this study, and to determine the incidence of different coping styles. Identifying the coping styles of good copers versus poorer copers would provide helpful insights for counsellors.

Using concept mapping to compare the ways in which (i) parents cope with other tragedies, and (ii) individuals cope with death would extend the understanding of the grieving process.

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Appendix A

Letter of Introduction

Dear Participants,

You will find enclosed a brief description of my research, 2 questionnaires (the green one to be completed by the father and the yellow one by the mother), and one postage paid envelope. While I would very much appreciate both parents participating in this study, if one parent only decides to do so, please mail your response.

Please complete your questionnaire independently and without consultation with your spouse, and mail to me c/o Dr. Peter Calder, my supervisor.

The sorting process will require about 1 hour of your time. Statements from the returned questionnaires will be printed on to cards. Your assistance is needed to place the statements that you think "go together" into piles. If you are willing to help with the sorting, please complete,135 cut off and return the form at the end of the questionnaire.

Thank you for participating in this research project.

Your sincerely,

Moira L. Sacks

Appendix B

DESCRIPTION OF RESEARCH PROJECT

Fathers' and Mothers' Responses to SIDS

I am a doctoral student, interested in learning more about the ways that mothers and fathers each deal with the sudden death of their baby. There is limited information reported in the literature relating to the ways in which fathers deal with the death of their child, and it is my hope to increase the body of knowledge in this area by fathers agreeing to participate as well as mothers. The results from this study will provide information which will be helpful for counsellors and support group facilitators working with parents whose baby died from SIDS.

Here is a brief description of my research study. A single question questionnaire will be mailed to each participant asking them to respond by listing all the ways that they have used/are using to deal with the death of their infant. The information will be returned to me for analysis.

Participants will be asked to assist in a sorting process for the analysis. This procedure will group the reported ways of dealing with the babies' deaths into themes. The sorting process will require about 1 hour of your time. Statements from the returned questionnaires will be printed on to cards. Your assistance is needed to place the statements that you think "go together" into piles. If you are willing to help sorting, please complete, cut off and return the form at the end of the questionnaire.

A survey questionnaire will be compiled from the original information collected and mailed out to participants. In responding to this questionnaire, participants will rate the most/least helpful ways of dealing with their baby's death, and also those that were used most/least frequently.

The results of this research will be published in my PhD thesis. Participation is **strictly voluntary** and there is **no need to identify yourself**. There is no need for you to complete the project should you choose to withdraw. If, on the unlikely chance, you find some of your thoughts disturbing feel free to contact myself and professional counselling can be arranged, if you so desire.

You will find enclosed a brief description of my research, 2 questionnaires (the green one to be completed by the father and the yellow one by the mother), and one postage paid envelope. While I would very much appreciate both parents participating in this study, if one parent only decides to do so, please mail your response.

Please complete your questionnaire independently and without consultation with your spouse, and mail it to me c/o Dr. Peter Calder, my supervisor.

I hope that you will consider participating in this project. Should you have any questions or concerns, please do not hesitate to call me at (403) 487 7156 and leave a message. I will return your call as promptly as possible.

Moira Sacks,
PhD Student in Counselling Psychology,
University of Alberta, Edmonton, Alberta.

Phone: 487 7156 (Home)

Appendixes C and D

First Questionnaire: Fathers' and Mothers' Responses to SIDS

Questionnaire for a Mother/Father

The participant understands that by answering the following questions that they do so voluntarily and in so doing they consent to participate in this study. At any time, the participant may withdraw from the study without penalty.

In analysing the information collected, participants are needed to help with the sorting process. If you would be willing to help with sorting, please provide your name, address and telephone number so that you may be contacted at a later date. Your identity will only be used for the purpose of contacting you for this process

Please provide the following information:-

1) Age of baby at time of death. ________________

2) Time since death of baby . ____________________

3) Birth order of this baby in the family.____________

Answer the following question by listing all the ways (actions, thoughts, feelings) employed in the space below.

What did you do to deal with the death of your baby from SIDS?

1)____

____

2)____

____

3)____

____

Appendix E

Agreement to participate in the sorting task

If you are willing to help with the sorting process, please complete the information below and mail separately from your response sheets to:-

Mrs. Moira Sacks
Dept. of Educational Psychology,
Faculty of Education,
6-141B Education North,
University of Alberta, Edmonton,
Alberta, T6G 2G5.

Name...

Address...

....

Phone...

Appendix F

Fathers' and Mothers' Response to SIDS

Consent to be Interviewed

The interviews will be audio taped, the tapes will be transcribed, and on completion of my thesis the tapes will be erased. The information from the interviews will be published in my PhD thesis: the participants identity will not be disclosed.

Participation in this study is strictly voluntary. You may withdraw from the interview at any time without penalty. If, on the unlikely chance, you find some of your thoughts disturbing feel free to contact myself and professional counselling can be arranged, if you so desire.

I hope that you will consider participating in this project. Should you have any concerns, please do not hesitate to call me at (403) 487-7156 and leave a message. I will return your call as promptly as possible.

Moira L. Sacks
PhD Student in Counselling Psychology
University of Alberta

I,.. understand the nature of this interview and agree to participate.

Signed..(Participant)

Signed..(Researcher)

Date..

Appendix G

Letter Requesting Help with Sorting

May 7th. 1996

Dear Participant (Father),

Fathers' and Mothers' Responses to SIDS.

I am currently carrying out a study to learn more about the ways that fathers and mothers deal with the death of their baby to Sudden Infant Death (SIDS). The results from this study will provide information which is helpful for counsellors and support group facilitators working with parents whose baby died from SIDS.

Fathers and mothers whose baby died from SIDS have already participated and generated statements of ways in which they coped with their baby's death. Each father's statements were pooled together to form a master list. The mother's statements were handled in the same way as the fathers. This phase of the study involves sorting the statements into groups to develop themes about the ways in which mothers and fathers responded to the death of their baby.

If you are willing to participate in this study by sorting the enclosed statements, please take a few minutes to complete the task described on the page 2. Fathers are asked to sort the statements provided by SIDS fathers. When you have completed the task, please place the materials in the return envelope and put it in the mail.

Your participation in this study is voluntary and you can withdraw at any time. Please do not sign your name. Your responses will be completely confidential and only group results will be used. Return of the statements and record sheet will be viewed as consent to participate.

If you have any questions, please phone me at 487-7156.
Your help is very much appreciated.
Thank you.

Moira L. Sacks
Ph.D. Student in Counselling Psychology,
Department of Educational Psychology
University of Alberta.

Peter Calder, Ph.D. (Professor)
Department of Educational Psychology
University of Alberta.

Appendix H

Fathers' and Mothers' Responses to SIDS

Please find enclosed:-

1) A set of statements; each statement is numbered and on a separate slip of paper.

2) A sheet of paper for recording the numbers of the statements that you decided to sort together.

3) An addressed envelope in which to return the statement slips and the record sheet.

The instructions for sorting are as follows:-

1) Sort the statements in any way you like such that the groupings of the statements contain a common theme.

2) Each statement can only be placed in one pile (one statement cannot be placed into two piles simultaneously).

3) All statements cannot be placed into a single pile.

4) Statements can be sorted as single items if you do not think that they fit into any group.

5) Record the statement numbers you have sorted together in each group on the record sheet.

6) Staple each pile of statements together. Write a possible title reflecting the theme of each group of statements on the top statement of each pile.

7) Mail the record sheet for sorted statements and the statement slips stapled together in the envelope provided by **May 16, 1996.**

Example of sorting procedure.

Statements:
1) The best way for me to unwind is by listening to music.
2) I relax listening to music.
3) I find music very soothing.

Theme of statements: Music is relaxing.

Record as follows:-

Pile Number	Statement numbers in pile
1	1, 2, 3

Appendix H (continued)

page 2

RECORD SHEET FOR SORTED SIDS MOTHERS' STATEMENTS.

Pile Number Statement Numbers

Appendix I

Mothers' original statements from interviews, telephone interviews, and questionnaires. (Highlighted statements indicate new information in response).

Mother #1

1. **I phoned my husband.**
2. **Our minister came over.**
3. **We wanted to see the baby so a friend phoned and asked them to stop the tests so we could go in the morning.**
4. **The coroner answered our questions.**
5. **I phoned my parents and I phoned my spouse's parents.**
6. **We went to visit a couple who had recently lost a baby.**
7. We talked to the minister.
8. The minister came over a couple of times and helped us.
9. **We had lots of friends round.**
10. **We talked to the parent support line.**
11. **We went to the support group meeting.**
12. We talked to two different families that answered the phone.
13. **We went to the support meeting and took our babysitter.**
14. We've been going to the support group meetings ever since.
15. **I just run the fund raising committee for family fun day.**
16. **Then I got on to the executive (SIDS chapter).**
17. **I went to the library and read all the books.**
18. **I tried to let people know people know that if they did what I had done, they should go to the library because a lot of it (information) is not right and not feel guilty.**
19. **I blamed God more.**
20. **I haven't been back to church.**
21. **You know if I did not turn away from seeing babies, that would have been a step forward.**
22. I want to do whatever I can to raise money for research.
23. I go to support meetings to listen.
24. **We got pregnant right away.**
25. **I tried to keep busy and stuff.**
26. **I wanted pictures (of the baby) developed right away.**
27. **I sent everybody pictures and copies of the funeral.**
28. **I kept a journal for awhile.**
29. **I kept a lot of the baby's clothes and stuff.**
30. **We had to move but** I kept the clothes hanging in the closet.
31. I knew I was going to have another baby.
32. **It didn't bother me to look at the baby's clothes and everything.**
33. I never gave anything away until now.
34. I kept some things and gave some away.
35. **I was mad because I wanted to be a mother.**
36. **You know, in your mind I guess, you are still a mother but physically there's no baby.**
37. **I went to our family doctor.**
38. **Having another baby was good for us.**
39. We went to the SIDS meetings.
40. **We had lots of support.**
41. **We have a good marriage, we talk and so it's okay.**

42. It's knowing that there is a child coming.
43. I just kept busy.
44. I was pregnant again and I was out shopping.
45. We moved when the baby was 5 months old.
46. We couldn't decide about the funeral arrangements and finally after 3 months we found out what other people had done.
47. We brought the baby (remains) home and when we moved he came with us.
48. I know that it is nothing that people have done ; the babysitter or ourselves.
49. I've done a couple of in services for Victims Services.
50. Not too much crying.
51. I know the baby's in heaven.
52. I've gone to two conferences (SIDS), national conferences.
53. At the funeral and the viewing, I didn't look at the baby because there was something missing.

Mother #2

54. I was very consumed with the funeral arrangements.
55. The first week I can't really say that it really hit me, I understood the baby had died.
56. We were very busy with the funeral.
57. We didn't go into the baby's bedroom; we kept the door shut.
58. We moved from the house four months later.
59. Nothing was touched in the baby's room.
60. I was pregnant again; I could not bring a baby into that house.
61. I felt very alone: I suppose the support feeling was gone after the funeral was done.
62. I felt very alone.
63. I remember looking out of the window or waiting for the phone to ring: it was a sense of being very deserted.
64. I would go out.
65. Picking up my other child from play school was a good excuse to stop at the mall.
66. I needed to get out.
67. I tried to find places where I would not see babies.
68. I didn't go into baby departments.
69. I avoided the play and park areas.
70. I distanced myself from babies.
71. I wanted to get pregnant again, right away.
72. The baby gave me something to look forward to; it did me a lot of good to be pregnant, it felt that was the best thing for me.
73. I felt the pregnancy filled a void, it didn't replace.
74. I had no desire to get out of bed.
75. I think the older children helped as I had to get up and do things for the kids.
76. I was still a mother.
77. I have a lot of guilt; I feel if I had gotten up and feed her, that things would have been different.
78. I deal with a lot of guilt; you know the "what if?'.
79. The guilt was the major factor and just feeling lonely.
80. I was mad, like I was very angry.
81. I couldn't understand.
82. I dealt with a lot of anger about why it happened.
83. I had anger inside me.
84. I was a lot shorter with my kids, I just wanted them to leave me alone.

85. I just wanted to be left alone.
86. I talked to friends who had lost a child.
87. I talked to a parent who had lost a child.
88. **I don't think I blame God, I'm indifferent.**
89. **I talked to my spouse's mother because I was hurting.**
90. **If I had a really down day, I would sit in the baby's room.**
91. **I would read the sympathy cards and touch her things.**
92. I would just go and sit in her room in the rocking chair and read cards.
93. I got a few books from friends and I would read those.
94. I went to the library and took out every book on SIDS.
95. **I was particularly interested in how other people felt: I was particularly interested in if there were any stories that were the same as mine but I would feel better knowing I wasn't alone.**
96. **It would upset me and I would get very emotional reading stories that were the same as mine.**
97. **I was on my maternity leave but went back to work early.**
98. I wanted to be out working.
99. **I volunteered.**
100. I took on a great number of things to keep me busy.
101. Once we had moved a lot of the need to be busy left.
102. I could not bring myself to put the baby's things away.
103. I have one box in my room that's full of some of the baby's personal things.
104. **I don't find going to the cemetery helpful.**
105. I would read through the interview books (SIDS) and have a good cry.
106. Looking through the baby's things, as much as it upsets me and depresses me, it makes me feel better.
107. I go to the SIDS groups and when hear stories from new parents, I'll have a really good cry.
108. **There's times when I just put it out of my mind.**
109. **I try to remember as much as I can.**
110. We (Husband and wife) talked a lot about, you know, it was so hard.
111. I can to talk to my mother-in-law any time.
112. By ignoring it, like on the baby's birthday, that upsets me; **it's easier to acknowledge that the baby lived.**
113. I phoned the SIDS 24 hour line.
114. We went to our first support group meeting in January.
115. **I asked someone from the SIDS group to talk at the funeral.**
116. We went pretty faithfully for the first year (SIDS group).
117. I wanted everybody at the funeral to know, you know, this is SIDS.
118. It was important to me that everybody understood what had happened.
119. I found I tried to give them (pregnant friends) information.
120. I found I was soaking up information.
121. **If they absolutely prove that it is the brain stem theory, then there is nothing I could've done, nothing anybody could have done.**
122. I can't imagine losing a first one: I still had my kids that I had to get up and look after.
123. The loneliness isn't there any more but **the emptiness still is.**
124. **I had to go on.**
125. I kept a journal.
126. The SIDS group helped a great deal.
127. **There's five, six , eight people in the room (support group) that feel the same way. It**

was nice to know that someone else had these feelings and had gone on.
128. You never forget, but life goes on and that's a fact.
129. I just kept busy the less time I had to think the better.
130. **I could not have made it through without my husband.**

Mother #3

131. I went to the SIDS Foundation parent support group.
132. **I went for counselling.**
133. **I took medications.**
134. **I was hospitalized.**
135. I was actively involved in SIDS activities such as fund raising.
136. I wrote letters to appropriate government officials re more funding for SIDS research.
137. **I tried, unsuccessfully, to have another child.**

Mother #4

138. **I am very thankful that I got to see my baby in the hospital after the baby passed away.**
139. I am very thankful for the support given to us by family and friends.
140. The memories that I have of my baby helped me a lot to deal with the death.
141. We buried our child back home.

Mother #5

142. Initially we went to three or four meetings of the SIDS parent support group.
143. I did a lot of information seeking.
144. I looked for work and kept myself busy with anything that would distract me.
145. **I grieved terribly, I was devastated and emotionally destroyed.**
146. I spoke with a psychologist once and my family doctor several times.
147. I had to go on an antidepressant for 4 months.
148. My husband and I became very close.
149. I've had family and friends who've been very supportive and this helped immensely.
150. I had to muster up every ounce of strength and will power I could to keep myself going and try to be positive in carrying on with life.

Mother #6

151. I cried and cried.
152. Friends and family were here.
153. My spouse and I would sit crying and sharing memories.
154. We slept on the couch, it was like we were afraid to fall asleep.
155. I didn't take medications.
156. Friends called the SIDS line, we had real good support.
157. We talked to the SIDS Foundation.
158. We repeated to ourselves that we couldn't do anything (about the baby's death).
159. I tried not to feel guilty.
160. **We went away.**
161. We took the album of the baby to share with friends.
162. We cried and cried.
163. **We did some normal things: the first time I laughed it was strange.**
164. **Some days it was difficult to one foot in front of the other.**

165. A black cloud was following us; **I felt like a failure.**
166. Why has this happened to me? Has it happened for a reason?
167. I joined SIDS and soon I was on the executive.
168. I wanted to raise public awareness.
169. I was devastated.
170. Within 1 month I was pregnant.
171. The next baby was a healer.
172. **I blanked out major blocks of time.**
173. I went to the funeral.
174. **I was a complete basket case.**
175. **I was floating on a different plain, going in and out out of it; you cruise on automatic pilot.**
176. I went back to work.
177. I did not pack up right a way, I shut the door and left the baby's room as was.
178. We gutted the basement because we needed something to do.
179. **Before the next baby arrived, we cleaned everything, carpets, furniture etc just in case.**
180. **I broke down one day.**
181. **The second baby slept in our room.**
182. I worry about my husband.
183. I went to a counsellor (hypnotherapist) because of my negative thoughts about the baby and my husband.

Mother #7

184. I tried to do everyday tasks with the family.
185. I read up on SIDS.
186. I borrowed every book from the Health Unit.
187. I spoke to my spouse a lot.
188. I was told by a friend that life goes on.
189. I went to two to three SIDS meetings.
190. I cried.
191. **I finally accepted the situation.**

Mother #8

192. I continued to go to school and work.
193. I got in touch with the SIDS chapter.
194. I got information and read all I could.
195. I laid out pamphlets (about SIDS) at the funeral and encouraged people to read them.
196. I went to a support meeting with the baby sitter.
197. I made contact with SIDS parents and talked over the phone.
198. I went to the doctor for technical information.
199. The biggest part of dealing with death was talking about it, I believe I talked to my husband.
120. **My other children were 11 and 9 years, I talked to them and answered their questions.**
201. I got film developed.
202. I phoned relatives to see if they had photos.
203. **I made the funeral arrangements: I arranged for friends to sing and play the organ.**
204. Making arrangements at the funeral home, my husband and I were laughing; was there something wrong with me?

205. I thought I was going crazy.
206. **I had difficulty afterwards (after baby's death) with ambulance sirens; I would be crying my eyes out wondering if it were a baby.**
207. **I check my children and husband when sleeping.**
208. Since then I have had two babies.
209. I had support from a SIDS mother.
210. I continued to be active in the Chapter and Board of Directors (SIDS).

Mother #9

211. **I wailed and called "Lord Jesus" over and over.**
212. I phoned my husband.
213. I phoned a friend to get my husband.
214. I sat on the stairs and just praised God, over and over.
215. Friends came and we went to friends.
216. I phoned my mother and she came later.
217. I was comforted by my daughter who said "you still have us".
218. I talked about anything; I talked about having the baby back.
219. **I was overwhelmed by my grief.**
220. I said "God help", god's strength came upon me.
221. It was difficult to go to the funeral.
222. It was a relief to see the body: that's not my baby.
223. I was falling apart.
224. I'm glad we've got some pictures of the baby.
225. **I questioned my husband as to how he felt; it was a relief to know my husband was still grieving and cared about the baby.**
226. We had a following of many friends who gave support.
227. I had a tremendous desire for another baby.
228. **We adopted a baby after years of prayer.**

Mother #10

229. I contacted the SIDS group for support.
230. **I went to church.**
231. I got support from my family.

Mother #11

232. I went to a few SIDS meetings.
233. I used the 24 hour line for SIDS often initially.
234. I had friends who listened.
235. I helped my baby sitter to deal with the death.

Mother #12

236. I talked to other SIDS parents, over and over.
237. I got involved in SIDS Foundation.
238. I read everything I could find on SIDS, grief and death.
239. I allowed myself to go through the grieving process.

Appendix J

Fathers' original statements from interviews, telephone interviews, and questionnaires. (Highlighted statements indicate new information in response.)

Father #1

1. **I talked a lot about it at work.**
2. **We had a funeral.**
3. **I ended up bawling and crying.**
4. **I drank a lot.**
5. I did a lot of talking about it.
6. **I did not talk that much about it with my spouse.**
7. **My spouse and I had a big fight because I talked more to others.**
8. I drank a little a bit more after the baby died.
9. **I really felt depressed.**
10. **I would go for a jog.**
11. I would do some exercise.
12. **I talked to somebody on the SIDS line.**
13. I would talk to someone.
14. If I talked to someone I'd be OK.
15. **I fought them at work so that I could have time off to attend the SIDS meetings.**
16. I had verbal fights with people when they said the wrong things to me.
17. **I pretty much said hell to religion.**
18. When things got too much I sneaked off to the bar.
19. **We had the baby cremated.**
20. **I wanted to be there when the baby was cremated.**
21. **I didn't go to the cremation because it would hurt everyone.**
22. **I was glad when I knew the body was gone.**
23. **When I visited the funeral home, I knew my child was not in that body.**
24. **I was devastated.**
25. I was in tears and everything.
26. I probably ran longer, probably more.
27. **I did a lot of day dreaming and thinking while I jogged.**
28. **I remember planning out the music for the funeral and things like that.**
29. **I was able to talk to my dad for a while.**
30. My spouse and I had two huge fights.
31. **We had decided that we would have another child.**
32. **I was scared to death to see my friend's baby.**
33. After our next baby was born, I was very scared.
34. **I checked the next baby three to four times during the night.**
35. **My biggest fear is remembering the baby.**
36. **I organised the 24-hour SIDS line.**
37. **I run as many parent support groups as I can make.**
38. **I like to think that I do everything in the baby's name.**
39. **I am happy having the baby's cremated remains in the house.**
40. I brought them (baby's ashes) home.
41. It was important to have the baby's cremated remains in a warm house full of love.
42. **I would give my spouse a hug.**
43. **I would talk to my spouse.**
44. **Sometimes I might really hurt.**

45. I might call the SIDS line.
46. I felt helpless to help my spouse.
47. I turned to my work friends an awful lot.
48. I turned to the minister at first.
49. I felt the people at work could help me more.
50. I thought I was running away from it by drinking.
51. I thought that I wouldn't be lucky enough to have children after the baby died.
52. I wouldn't be lucky enough to have children after the baby died.
53. I was just focusing my anger.
54. I felt very angry about being told not to attend those (SIDS) groups.
55. I thought God never figured I was a good enough parent so he took my baby away from me.
56. I don't really know why it happened.
57. I don't think anybody was punishing me or my spouse.
58. I don't know what I believe any more.
59. I don't know if I believe God has that much control over our lives.
60. I don't know if things are predetermined.
61. I'll meet my baby in heaven.
62. I'll know everything and understand it when I get to heaven.
63. This was a body, the baby has gone, I don't know where.
63. I have a little angel on my shoulder that protects me on bad days.
64. I don't think that I would have made it without the SIDS group or some kind of group.
65. I feel good having the baby's cremated remains at home.

Father # 2

66. I cried and cried for a long time.
67. I almost had a break down.
68. I called family and friends.
69. I lost track of time.
70. I was staring into the distance and crashing back to reality.
71. I phoned the SIDS help line.
72. I went on my own to all the meetings over the next 6 months.
73. I stopped at the baby's grave every couple of days.
74. I talked with my cousin.
75. At first I talked to my spouse.
76. The prospect of a new baby helped.
77. My wife and two year old boy kept me going because of my responsibility to them.
78. Thinking about my eldest child helped.
79. I often asked "Why did a little baby go. Why not somebody else like me?"
80. I remember lots of pain at the loss.

Father #3

81 At first I felt hollow, a big hole.
82. I had a hard time.
83. I knew he was gone.
84. I just let go.
85. I felt very bad.
86. I couldn't understand, the world wasn't stopping, mine had.

87. I didn't want to pack up the baby's belongings.
88. I had bad dreams; I didn't work any more.
89. We went away with my spouse's relatives.
90. I had a hard time.
91. We kept baby's door closed.
92. I don't talk about it a lot.
93. I remember the baby's birthday and Christmas.
94. We had a new baby.
95. With the second baby it was very hard.
96. I talked to a friend.

Father #4

97. I became more patient.
98. Life became more important than work.
99. I suffered a lot of depression.
100. I found it hard to concentrate on anything.

Father #5

101. I said "God you've always been there for us."
102. I prayed a lot.
103. We called friends who wept and prayed with us.
104. I had a revelation about the importance of life being quality.
105. Talking was significant.
106. I remember the last night I spent with my baby.
107. I always acknowledge the baby as part of the family.
108. I communicated with my spouse.
109. We visited the grave site.
110. I think the baby has been spared.
111. When I saw the baby laid out, the body was there the baby was not.

Father #6

112. I think you hang on to any permanent type of life lines that are open.
113. I found the emergency response team very sympathetic and protective.
114. I didn't cry until we were in the case room.
115. I found the SIDS help line beneficial.
116. I found the SIDS support group sessions beneficial.
117. I think I've only missed three to fur support groups over the years.
118. I talked to an aunt who had lost a child.
119. I talked to others who understood because they had lost a baby.
120. I talked to my spouse.
121. My spouse and I mull things over.
122. You see people who have gone through it and still attend the group: and it's the "Yeah" you can live.
123. Having support of family and friends.
124. Our older children needed to be looked after.
125. Our older children still needed their parents.
126. The SIDS films.
127. I say I have four children, I lost one to SIDS.

128. I say I have the number of living children when I am having a bad day.
129. I talked when I felt **I could talk without falling apart.**
130. Understanding was initially very important.
131. The SIDS group was very helpful.
132. **I believe there is nothing we could have done to prevent it (death).**
133. **I could ask questions at SIDS meetings.**
134. **I could get answers at SIDS meetings.**
135. I was afraid that something would happen to our next baby.
136. **I woke up every five minutes and rushed into the room with the next baby.**
137. I wake up and go to the children's room to make sure that they are okay.
138. When I come home the first thing I do is check the children.
139. If the baby sleeps 15 minutes too long, I listen at the door or go in to see if everything is all right.

Father #7

140. We joined a SIDS support group.
141. **We began to go to church.**
142. We asked God "Why?"

Father # 8

143. **I believe in nature's way.**
144. **I kept on working.**
145. **I helped my spouse get over it.**
146. Working kept my mind from thinking about it.

Father # 9

147. I spent a great deal of time playing the piano.
148. I focused on physical labour
149. I tried to put it into the natural scheme of things.
150. Overwhelming emptiness.
151. I was angry.
152. I felt a sense of heaviness.
153. I rationalizes that perhaps this was better than having a severely disabled child.

Father # 10

154. I attended one parent support meeting.
155. I kept thinking of the two other children.
156. I kept thinking life must go on
157. I worked a lot of overtime.

Father # 11

158. I was angry at myself because I should have protected my baby.
159. I talked to people about; friends and family were willing to listen.
160. My wife and I became closer.
161. I would wake up at night to see if my wife was breathing out of fear that she might just stop breathing.

Appendix K

Grouping of mothers' statements from initial editing.

Question: How did you deal with the death of your baby from Sudden Infant Death Syndrome (SIDS)?

Groupone

1. We went to visit a couple who had recently lost a baby
2. I talked to friends who had lost a child.
3 I talked to another parent who had lost a child.
4 I made contact with SIDS parents.
5. I had support from a SIDS mom.
6. I talked to other SIDS parents.
7 We had the minister over.
8. We talked to the minister.
9. We got help from the minister.
10. I phoned my spouse.
11. I talked to my spouse.
12. I talked a lot to my spouse.
13. I spoke to my spouse a lot.
14. We (my spouse and I) talk.
15. I questioned my spouse about their feelings.
16. I phoned a friend.
17. I phoned my parents.
18. I phoned my mother.
19. I phoned my spouse's parents.
20. I talked.
21. I talked to my spouse's mother.
22. I had friends who listened.
23. I can talk to my mother-in-law.
24. I talked to my children.
25. I answered my children's questions.
26. We asked the coroner some questions.
27. We wanted to see the baby.
28. I am very thankful that I got to see my baby .
29. We had lots of friends round.
30. I am very thankful for the support given to us by friends.
31. We had support from many friends.
32. We went to friends.
33. Family and friends were very supportive.
34. I got support from my family.
35. We had family and friends.
36. We had good support.
37. We had lots of support.
38. I am very thankful for support given to us by family.
39. We went away.
40. We did some normal things.
41. I tried to do everyday tasks with my family.
42. I went for counselling.

43. I spoke with a psychologist.
44. I went to a hypnotherapist.
45. I went to the doctor for information.
46. I went to our family doctor for information and advice .
47. I spoke with my family doctor.
48. I took medications.
49. I had to go on an antidepressant.
50. I was hospitalised.

Grouptwo

51. I tried to keep busy.
52. I just kept busy.
53. I just kept busy.
54. I kept myself busy.
55. I took on a great number of things to keep myself busy.
56. We gutted the basement.
57. We needed something to do.
58. I was out shopping again.
59. I went out.
60. I needed to go out.
61. Picking up my child from play school was a good excuse to go to stop at the mall on the way home.
62. I continued to go to school.
63. I continued to go to work.
64. I went back to work .
65. I went back to work early.
66. I wanted to be out at work.
67. I looked for work.

Group three

68. I went to the library
69. I went to the library.
70. I borrowed a book from the health unit.
71. I read all the books.
72. I read up on SIDS.
73. I read books.
74. I read everything I could find on SIDS,grief and on death.
75. I would read through the interview books.
76. I took out every book on SIDS.
77. I got all the information I could read.
78. I was soaking up information.
79. I did a lot of information seeking.
80. I encouraged people to read the information put out at the funeral.
81. I asked someone from the SIDS group to talk at the funeral.
82. I wanted everybody at the funeral to know what SIDS is.
83. It was important to me that everybody understood what had happened.
84. I tried to inform people about SIDS so that they would not feel so guilt.
85. I wanted raise public awareness.
86. I tried to give pregnant friends information.

87. I was interested in seeing how other people felt.
88. I was particularly interested if there were any stories in the book that were the same as mine.
89. I found it nice to know that someone else had these feelings and gone on.
90. I felt I was not alone after reading other people's stories.
91. We found out what other people did with the baby's body.
92. My spouse and I made the funeral arrangements.
93. We were very busy with the funeral.
94. I made the funeral arrangements.
95. I went to the funeral.
96. I went to the funeral.
97. We buried our baby back home.
98. We brought the baby's remains home.
99. When I saw the baby at the funeral there was something missing.
100. I was relieved to see that body was not my baby.

Groupfour

101. We talked to the SIDS Foundation.
102. We talked to the parent support line.
103. We talked to two different families that answer the phone.
104. I phoned the SIDS 24 hour line.
105. I used the 24 hour line for SIDS.
106. I talked to SIDS parents over the phone.
107. I got in touch with the SIDS chapter.
108. I contacted the SIDS group.
109. I went to SIDS meetings.
110. We went to the support group meeting.
111. We have been going to the support group meeting ever since.
112 I went to the SIDS meetings.
113. I attended parent support groups (SIDS Foundation).
114. I go to the parent support groups to listen.
115. We went to our first support group meeting.
116. I went to 2 or 3 SIDS meetings.
117. We went to 3 to 4 meetings of the SIDS parent support group.
118. We went pretty faithfully to the SIDS group for the first year.
119. Going to the SIDS support groups helped.
120. We got support from the SIDS group.
121. I was an active member of the SIDS chapter.
122. I joined the SIDS chapter.
123. I became involved with the SIDS Foundation.
124. I helped my baby sitter deal with the death.
125. We took our babysitter to the support group meeting.
126. The babysitter and I went to a support group meeting.
127. I run the SIDS fund raising committee for family fun day.
128. I was actively involved in SIDS fund raising activities.
129. I wrote letters to government officials to raise money for SIDS research.
130. I want to do whatever I can to help raise money for research.
131. I got on to the executive (SIDS chapter).
132. I was on the Board of Directors (SIDS).
133. I was on the executive.

7

134. I volunteered.
135. I have done a couple of in services for Victims Services.
136. I have gone to two national conferences.

Group five

137. I was so mad.
138. I was mad.
139. I was very angry.
140. I dealt with a lot of anger .
141. I felt anger inside me.
142. I did not cry too much.
143. I cried and cried.
144. We cried.
145. We cried and cried.
146. I wailed.
147. I had a really good cry.
148. I cried.
149. We were afraid to fall asleep.
150. I had a lot of guilt.
151. I dealt with a lot of guilt.
152. I know that guilt was the major force.
153. I tried not to feel guilty.
154. I would get depressed.
155 I had no desire to get out of bed.
156. I felt like a failure.
157. I was devastated.
158. I was devastated.
159. I blanked out major blocks of time.
160. I was floating on a different plain, going in and out of it.
161. I cruised on automatic pilot.
162. I found it difficult to put one foot in front of the other.
163. I was a complete basket case.
164. I questioned whether there was something wrong with me when I laughed.
165. The first time we laughed it was strange.
166. I thought I was going crazy .
167. I was falling apart.
168. I broke down one day.
169. I was emotionally destroyed.
170. I was overwhelmed with grief.
171. I grieved terribly.
172. I allowed myself to grieve.
173. I felt very alone.
174. I felt very alone.
175. I just felt very lonely.
176. I just had a sense of being deserted.
177. I think there is a kind of emptiness.
178. I was hurting.
179. I got upset.
180. I got very emotional hearing new SIDS parent's stories.
181. I got really upset.

182. I felt better.
183. I cried and wondered if it was a baby when I heard sirens.

Group six

184. I was a lot shorter with my children.
185. I just wanted the children to leave me alone
186. I just wanted to be left alone.
187. I still had my other children that I had to get up and look after.
188. I was comforted by my 5 year old child who said you still have the other children.
189. I think having the older children helped.
190. I had to get up and do things for the kids.
191. I was still a mother.
192. My spouse and I became very close.
193. My spouse and I became close.
194. We have a good marriage.
195. I could not have made it through without my spouse.
196. I was relieved to know that my spouse was still grieving and still cared about the baby.
197. We got pregnant right away.
198. I was pregnant again.
199. I was pregnant again.
200. I was pregnant again.
201. I had two more babies.
202. Knowing there's a child coming.
203. Having another baby was good for us.
204. I felt that the best thing for me was to have a baby.
205. I found the next baby healing.
206. I felt the pregnancy was something to look forward to.
207. I wanted to get pregnant right away.
208. I had a tremendous desire for a baby.
209. I prayed for a baby.
210. I knew I was going to have another baby.
211. I wanted to be a mother.
212. You know in your mind that you're still a mother but physically there is no baby there.
213. I felt the pregnancy filled a void.
214. I tried unsuccessfully to have another child.
215. We adopted a baby.
216. I could not bring another baby into that house.
217. We moved.
218. We had to move.
219. We moved.
220. We cleaned everything in the house before the next baby arrived.
221. I had the next baby sleep in our room.

Group seven

222. I know that the baby's death is nothing that people have done.
223. I could do nothing about the baby's death.
224. I could not have done anything (to prevent the death).

225. I finally accepted the situation.
226. I accepted the situation.
227. I had to find the strength to keep going.
228. I accepted the situation.
229. I was told by a friend that life goes on.
230. I had to go on.
231. I had to be positive.
232. You never forget, life goes on.
233. I just put it out of my mind.
234. I blamed God more.
235. I think that I'm indifferent (about God).
236. I did not go to church.
237. I called "Lord Jesus".
238. I praised God.
239. I asked God's help.
240. I went to church.
241. I know that the baby is in heaven.
242. If I could see babies and not turn away.
243. I tried to go places where I would not find a lot of babies.
244. I did not go into baby departments.
245. I avoided the play area in the park.
246. I distance myself from babies.
247. I just tried to distance myself.
248. I wanted the pictures of the baby developed right away.
249. I got film of the baby developed.
250. I phoned relatives to see if they had pictures.
251. I am glad we have pictures.
252. We took the album of baby pictures to share pictures with friends.
253. I sent everybody pictures of the baby.
254. I sent everybody copies of the funeral.
256. I read the sympathy cards.
257. I read the cards.
258. I kept a journal.
259. I kept a journal.
260. I kept a lot of the baby's clothes and stuff.
261. I kept all the baby clothes hanging in the closet.
262. I kept some things.
263. I never gave anything away until now.
264. I have a box of just the baby's things.
265. It didn't bother me to look at the baby's clothes and everything.
266. I touched the baby's things.
267. I could not put the baby's things away.
268. I did not pack the baby's things right away.
269. I shut the door and left the baby's room as it was.
270. We touched nothing in the baby's room until we moved.
271. We did not go into the baby's bedroom.
272. We kept the door to the baby's bedroom closed for a long time.
273. We shared memories.
274. The memories of my baby helped me a lot.
275. I try to remember as much as I can.
276. I get upset when the baby is ignored.

277. I find it easier acknowledging that the baby lived.
278. I sat in the baby's room.
279. I sat in the baby's room.
280. I check my children when sleeping.
281. I check my husband when sleeping.
282. I worry about my husband.
283. I could not understand.
284. I understood that the baby died.
285. I asked "Why has this happened to me?"
286. I asked "Has this happened for a reason?"
287. I cannot say that it really hit me for the first week.

Appendix L

Grouping of fathers' statements from initial editing.

Question:"How did you deal with the death of your baby from sudden Infant Death Syndrome (SIDS)?"

Groupone

1. I talked a lot about it at work.
2. I talked a lot.
3. Talking was significant.
4. I talked when I felt I could.
5. I would talk to someone.
5. I talked to a friend.
6. I talked to people.
7. I talked to my Dad.
8. I talked to my cousin.
9. I talked to an aunt who lost a child.
10. I talked to others who had lost a baby.
11. I talked to my spouse.
12. I talked to my spouse.
13. I communicated with my spouse.
14. I talked to my spouse.
15. My spouse and mull things over.
16. I did not talk that much to my spouse.
17. I do not talk about it a lot.
18. I drank a lot.
19. I drank more after the baby died.
20. I went to the bar.
21. I was running away from it by drinking.
22. I jogged.
23. I exercised.
24 I ran longer.
25. I focused on physical labour.
26. I did a lot of day dreaming and thinking.
27. I worked a lot of over time.
28. I kept on working.
29. Working kept my mind from thinking about it.
30. I played the piano a great deal.
31. I did not work any more.
32. I prayed a lot.
33. We called friends.
34. We had support of family and friends.
35. I got help from my friends at work.
36. I turned to my work friends an awful lot.
37. I called family and friends.
38. We went away.
39. We visited the grave.
40. I stopped at the baby's grave every couple of days.

41. I did not want to pack up the baby's belongings.
42. We kept baby's door closed.

Grouptwo

43. We had a funeral.
44. We had the baby cremated.
45. I planned the funeral.
46. I wanted to be there when the baby was cremated.
47. I did not go to the cremation because it would hurt everyone.
48. When I saw the baby laid out, the body was there but the baby was not.
49. I knew my child was not in that body.
50. This was a body, the baby had gone.
51. I was glad when I knew the body was gone.
52. I knew the baby was gone.
53. I am happy having the baby's cremated remains in the house.
54. I brought the baby's ashes home.
55. I feel good having the baby's cremated remains at home.
56. It was important to have the baby's cremated remains in a warm house full of love.
57. I cried.
58. I cried.
59. I cried and cried.
60. I cried.
61. I almost had a break down.
62. I felt depressed.
63. I suffered from depression.
64. I felt a sense of heaviness.
65. I lost track of time.
66. I was staring into space and crashing back to reality.
67. I felt overwhelming emptiness.
68. I found it hard to concentrate.
69. At first I felt hollow, a big hole.
70. I was devastated.
71. I fell apart.
72. I had a hard time.
73. I had a hard time.
74. I felt very bad.
75. Sometimes I really hurt.
76. I remember lots of pain.
77. I had bad dreams.
78. I was angry.
79. I was angry.
80. I was just focusing my anger.
81 I argued with people.

Group three

82. I had a fight with my spouse.
83. I fought with my spouse.
84. I gave my spouse a hug.
85. I helped my spouse get over it.

86. My spouse and I became closer.
87. I felt helpless to help my spouse.
88. Our older children needed to be looked after.
89. Our older children still need their parents.
90. I kept thinking of the other children.
91. Thinking of my eldest child helped.
92. My wife and two year old child kept going.
93. I will say I have 4 children, I lost one to SIDS.
94. I always acknowledge the baby as part of the family.
95. I say I have the number of living children when I'm having a bad day.
96. The prospect of a new baby helped.
97. We had decided to have another child.
98. We had a new baby.

Groupfour

99. I didn't work any more.
100. I said hell to religion.
101. I said "God you've always said that you'll be there for us".
102. I prayed a lot.
103. We began to go to church.
104. I turned to the minister first.
105. I thought that I would not be lucky enough to have children again.
106. I would not be lucky enough to have children after the baby died.
107. I thought God never figured I was a good enough parent so he took my baby away from me.
108. I could not understand.
109. We asked God "Why?"
110. I often asked "Why did a little baby go?"
111. I don't really know what happened.
112. I don't think anybody was punishing me or my spouse.
113. I don't know what I believe.
114. I don't know if God has much control over our lives.
115. I don't know if things are predetermined.
116. I will meet my baby in heaven.
117. I will understand everything when I get to heaven.
118. Understanding was initially very important.
119. I kept thinking life must go on.
120. I held on to any permanent type of the life lines.
121. I believe there is nothing we could have done to have prevented it.
122. I believe in nature's way.
123. I tried to put it into the natural scheme of things.
124. I rationalized that perhaps this was better than having a severely disabled child.
125. I think that my baby has been spared.
126. I have a little angel on my shoulder that protects me on bad days.

Group five

127. I organised the 24 hour SIDS line.
128. I ran as many parent support groups as I could.
129. I wanted time off work to attend the SIDS meetings.
130. I do not think that I would have made it without the SIDS group.?

131. I needed the SIDS group to get through?
132. I attended one parent support meeting.
133. I went all the meetings (SIDS).
134. I found the SIDS support group sessions beneficial.
135. I only missed three to four support groups.
136. The SIDS group was very helpful.
137. We joined a SIDS support group.
138. I talked to somebody on the SIDS line.
139. I called the SIDS line.
140. I phoned the SIDS help line.
141. I might called the SIDS line.
142. I found the SIDS help line beneficial.
143. Knowing that others have lived through the experience makes you see that you can live.
144. I asked questions at SIDS meeting.
145. I got answers at SIDS meetings.
146. I found the emergency response team very sympathetic, helpful and protective.
147. I watched the SIDS films.
148. I was scared to see my friend's baby.
149. I was scared when our next baby was born.
150. I found it hard with the second baby.
151. I was afraid that the same thing would happen to our next baby.
152. I checked the next baby three to four times during the night.
153. I woke up every five minutes and rushed into the room with the next baby.
154. I listen at the baby's door or go in to see that everything is okay.
155. When I come home the first thing that I do is check the kids.
156. I wake up and go to the children's room to make sure that they are okay.
157. I woke up at night and checked that my wife was breathing.
158. My biggest fear is remembering the baby.
159. I remember the baby's birthday and Christmas.
160. I remember the last night I spent with my baby.
161. I like to think that I do everything in the baby's name.
162. I became more patient.
163. Life became more important than work.
164. I realized the importance of life is the quality.